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# Self-Management of Type 1 Diabetes Across Adolescence: A Dissertation

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# SELF MANAGEMENT OF TYPE 1 DIABETES ACROSS ADOLESCENCE

A Dissertation Presented by

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*Self-Management of Type 1 Diabetes Across Adolescence*

A Dissertation Presented

By

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# Abstract

# SELF-MANAGEMENT OF TYPE 1 DIABETES ACROSS ADOLESCENCE

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Little is known about what variables affect self-management practices of adolescents with T1D. Few studies have examined differences in self-management behaviors by stage of adolescence. Similarly, no studies have examined all of the attributes of self-management, including Collaboration with Parents and Goals. In order to fill the gaps in the literature, a secondary data analysis with a descriptive correlation design was conducted to describe T1D self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals) during early, middle and late stages of adolescence. This study also examined whether the roles of covariates (regimen, duration of illness (DOI), gender) in self-management behaviors vary by stage of adolescence. Data from 504 subjects aged 13 – 21 years were analyzed and the age variable was transformed into three adolescent stages early (13-14) (*n*=163), middle (15-16) ( *n*=159) and late (17-21) (*n*=182). T

The findings revealed significant differences between adolescent stages on Collaboration with Parents and the Diabetes Problem Solving subscale. The covariate analysis showed no significant effect modification for the covariates and stage on any of the subscales so the results did not differ from the ANOVA model. Covariate analysis showed significant associations between regimen and Collaboration with Parents, Diabetes Care

Activities and Diabetes Problem Solving.  DOI showed significant associations only with Diabetes Problem solving and gender had significant associations with Diabetes Care Activities and Diabetes Communication.

The mean scores on Collaboration with Parents show an incremental decline in collaboration with parents as adolescents move through stages.  The higher mean Diabetes Problem Solving scores found in the late adolescent group compared correlated with a higher degree of problem solving in this group when compared to those in the early or middle adolescent stage group.  Regimen had significant associations with three of the five subscales suggesting this is an important variable for future study.  DOI did not have a significant impact on self-management whereas gender related differences in the areas of Diabetes Activities and Diabetes communication warrant further investigation.

# Chapter I

# State of the Science

## Introduction

### *Background and Significance*

Type 1 Diabetes (T1D) affects about one in every 400 to 600 children and adolescents which translates to approximately 186,300 youth under the age of 20 (American Diabetes Association [ADA], 2008). There are some potentially serious complications that can occur as a result of diabetes. Chronic complications are numerous and have multiple micro and macro vascular implications. Acute complications can be life threatening and include diabetic ketoacidosis (DKA) and hypoglycemia. Much of what we now know about preventing diabetes-related complications has come from the Diabetes Control and Complication Trials (DCCT) (1993). This clinical trial supported the use of flexible (commonly called intensive) over conventional regimens to increase metabolic control and decrease diabetes-related complications. The DCCT was primarily focused on adults, with a relatively small ($n$=215, 15%) sample being adolescent (13-17 years). There were 125 adolescents in the primary prevention group and 90 in the secondary prevention group. However, findings did show that blood sugar levels in adolescents were more difficult to control, and these participants experienced more episodes of severe hypoglycemia and DKA than adults in the study. Further research done by the Epidemiology of Diabetes Interventions and Complications (EDIC) (2001) Research Group supported the continued benefits of flexible regimens in adolescent patients to reduce the risk of long term complications. The benefits of decreasing long term micro and macrovascular complications were shown to outweigh the risks of acute complications such as DKA and hypoglycemia in those who were on flexible regimens. This led the ADA (2005) to recommend that patients over the age of 7 years should be managed with a flexible regimen to best assist them to achieve optimal glycemic control.

Self-management of diabetes poses different challenges for adolescents than for adults. During adolescence, teens become more engaged in self-management. They also experience physiological changes that increase insulin resistance (Brink, 1997). These changes require frequent changes in insulin doses that can result in fluctuating blood sugars complicating self-management. Their ability to think abstractly and contemplate the future begins to develop between 12-14 years of age (Epstein, 2001). However, even the most cognitively mature adolescent still tends to remained focused on the present (Kimmel & Weiner, 1995). Thus, expecting adolescents to have impeccable self-management behaviors to prevent diabetes-related complications is unrealistic. Additionally, the intrusive nature of diabetes treatment regimens has implications for self-management responsibility, especially when adolescents spend more time away from home. Socialization and the pressure to fit in with their peers may be a higher priority than practicing optimal self-management. This is especially problematic because diabetes is a condition that requires precise and ongoing self-management (Schilling, Grey & Knafl, 2002). These management requirements result in major lifestyle implications.

Of grave concern for adolescents are less than optimal self-management behaviors that may lead to medical complications. Of particular concern are acute episodes of DKA and hypoglycemia, which can be life-threatening. In fact, DKA is the single most common cause of hospitalization and death in patients with diabetes who are less than 24 years of age (Travaglini, Garg & Jelley, 1998).

Chronic complications are also a great concern for adolescents. Data from the EDIC (2001) suggested that poor glycemic control in the initial years after diagnosis had a significant effect on the progression of complications in later years, even if better glycemic control is later established. These chronic complications are numerous and include the onset and progression of retinopathy and neuropathy, stroke, myocardial infarction, sexual and urological problems, kidney disease and stomach nerve damage (National Institute of Diabetes and Digestive and Kidney Disorders [NIDDK], 2008). Further, it has been suggested that the adolescent period is an important time for establishing health habits that influence future health (Madsen, Roisman & Collins, 2002). Therefore, it is important to understand which variables may pose risk and protective factors for adolescents with T1D.

Factors predicting optimal self-management in the adolescent population remain unknown (Sawyer & Aroni, 2005). Although it is important to understand self-management behaviors in adolescence, there are few studies in the extant literature that describe these behaviors by adolescent stage (early, middle, and late). It has been suggested that self-management changes over the course of adolescence (Schilling, Knafl & Grey, 2006) and development is a gradual, dynamic and individualistic process. Developmental changes within adolescence such as cognitive, psychosocial, emotional, physiologic (biological hormone) and physical (psychomotor) changes may moderate self-management behaviors. For example, biological changes at the onset of puberty in early adolescence make glycemic levels more difficult to maintain secondary to insulin resistance (Brink, 1997). During middle to late adolescence abstract thinking evolves, thus allowing adolescents to fully consider the impact of their condition and consequences associated with it (Pettersen & Leffert, 1995). During late adolescence, social changes such as the final years of high school and college transition influence self-management (Madsen et al., 2002). Because of the individual developmental variations present in any one chronological time point, it more useful to consider a range, or adolescent stages, to account for developmental variations.

### *Specific Aims*

In order to fill the gaps in the literature, the purpose of this secondary analysis is to describe T1D self-management behaviors in early, middle and late stages of adolescence. The specific aims are to:

1) Examine differences in self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals) in early, middle and late adolescence.

2) Examine whether the roles of covariates (duration of illness: DOI, regimen, gender) in self-management behaviors vary by stage of adolescence.

A description of the factors that influence self-management behaviors is important to begin to understand how to best support adolescents and their parents in achieving and maintaining optimal self-management. The results of this study will potentially provide new insight into risk or protective factors that may influence self-management behaviors during three stages of adolescence. This information could then be applied to target age-specific adolescent-parent interventions that mitigate risk factors and augment protective factors that facilitate self-management, as well as to assist in the transition to adult care.

## Overview

### *Type 1 Diabetes*

There are 13,000 individuals diagnosed with T1D annually (most of them are under the age of 20) contributing to the approximately 186,300 youth under the age of 20 who have been diagnosed with T1D (ADA, 2008). T1D is a condition characterized by lack of insulin production that occurs when the body's immune system attacks and destroys the beta cells that normally produce insulin (Juvenile Diabetes Research Foundation [JDRF], 2008). Insulin is a hormone that is necessary to move glucose into cells, so without it glucose stays in the blood where it does not produce energy for the body to function. Because the individual is lacking endogenous production of this hormone, it is essential to give exogenous insulin to maintain metabolic function and sustain life. In addition to insulin administration, individuals with diabetes must also monitor blood glucose levels and treat hypoglycemia with a quick-acting carbohydrate. Dietary intake must also be monitored and adjusted, specifically the amount of carbohydrate intake.

The current treatment guidelines from the ADA (2005) suggest using flexible treatment for children over the age of 7 years. Table 1 outlines some of the differences between the two treatment regimens. Flexible regimens are designed to achieve and maintain optimal blood glucose levels that mimic those in individuals without diabetes, while minimizing the potentially life threatening side effects of this treatment regimen. This type of regimen allows for a greater flexibility with meal planning (times, content), but also requires multiple blood glucose testing and insulin boluses. Conventional regimens do not allow for as much metabolic control or flexibility, but do offer a decreased likelihood of some of the life threatening complications associated with flexible regimens, such as DKA and hypoglycemia. Regardless of the treatment regimen selected, administration of insulin is essential. For flexible regimens this can be done through a constant subcutaneous insulin infusion device (CSII) (also referred to as a pump) or multiple daily injections (MDI), (commonly four but as many as eight daily). Conventional regimens also require exogenous insulin but may be administered less often.

Table 1. Differences in Conventional and Flexible Regimen

| Regimen Type | # of Insulin Administration and/or Dose Adjustments | # of Blood Glucose Monitoring (BGM) per Day | Dietary Impact |
|---|---|---|---|
| Flexible | 4-8<br>ideal 6-7 | 4-8<br>at least 4 times per day & with exercise and nocturnal glucose monitoring | Flexible meal times, content determines insulin dose |
| Conventional | 2-4<br>2-3 may not be enough for adolescent patients | 2-4<br>*at least 4 times per day & with exercise and nocturnal glucose monitoring | Predetermined, timed meals/snacks and dietary content |

Adapted from "Effect of flexible diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus" by Diabetes Control and Complications Trial (DCCT) Group, 1994, *Journal of Pediatrics*, *125*, 177-88 & "Care of children and adolescents with Type 1 Diabetes, A statement of the American Diabetes Association (ADA)", by Silverstein et al, (2005), *Diabetes Care*, 28(1), 186-212.

## Review of the Literature

The purpose of this chapter is to review the theoretical literature on adolescent development to provide a context for understanding development and the influence this has on self-management behaviors. A further intent is to summarize the cognitive, psychosocial, emotional, physiological and physical (psychomotor) development in adolescence. In this chapter, recent research relevant to the concept of self-management: (process, activities, and goals) will be reviewed by stage of adolescence (Schilling et al., 2002) and empirical studies related to regimen, duration of illness (DOI), and gender.

## Adolescence

The term *adolescence* came in use in early 1900 when G. Stanley Hall's book, *Adolescence* (1904) referred to it as "the definitive term for the elongated hiatus between childhood and adulthood" (Hall, 2007, p. 2). Adolescence is a Latin word that means to *grow* into maturity. As the name suggests, it is a period marked by significant and rapid biophysical, social and cognitive growth, all of which contribute significantly to the complex nature of this life stage (Petersen & Leffert, 1995).

### *Age and Stage of Adolescence*

There are several subphases within adolescence, often referred to as stages: early, middle and late. The labeling of these stages of adolescence came from Peter Blos (1962) who described six stages of development beginning from childhood to adulthood (Kimmel & Weiner, 1995). There is a considerable amount of variation among scholars in what chronological age corresponds with each stage of adolescence. In order to better understand some of the developmental milestones that occur during different points in adolescence, the first part of this chapter will focus on cognitive, psychosocial, emotional, physiological, and physical/psychomotor development.

Age is a key variable in the study of stages of adolescence and there are several ways in which age has been reported in empirical work. Most reports include a range of ages, for instance, range from 12- 20, mean 14.2 years +/- 1.9 (Anderson, Bracket, Ho & Laffel, 1999; Grey, Boland, Davidson & Tamborlane, 2000). There are some studies that report only the mean age for the study sample. For example, Hains and colleagues (2006) have reported the mean age as 13.94 years from their sample. Similarly, Streisand, Respess, Overstreet, Gonzalez and Pjem (2002) in a study of self-care behaviors in urban youth reported a mean of 12.6 years of age. Many studies report a limited age range within adolescence, while others reported a very wide range of youth (e.g. ages 8-16), including younger children as well as adolescents (Faulkner & Chang, 2007; Skinner & Hampson, 2001).

Less common, but useful, are those studies that reported findings by stage of adolescence, hence grouping adolescents of like developmental stages together, thus enabling results to be interpreted for cohorts of early, middle and late adolescents (Christie & Viner, 2005; Schmidt, 2007). Grouping ranges of chronological ages into stages assists researchers and clinicians alike by accounting for some of the developmental variation present at any given chronological age point. Unfortunately, there is a lack of continuity in the literature in regard to which chronological age range corresponds with each stage of adolescence. As illustrated in Table 2, no two studies in the adolescent diabetes literature report this variable the same way. In fact, some authors have reported adolescent stages differently within their own work. This is problematic, especially when trying to synthesize data from multiple reports.

In their review of behavioral interventions for children and adolescents with T1D, Hood and Nansel (2007) highlighted the importance of using of developmental theory to develop and implement interventions targeted to optimize self-management behaviors. Analysis by stage of adolescence (early, middle and late) will assist clinicians and researchers to synthesize data to better understand which risk and protective factors are most likely to influence which groups. Further, analysis by developmental stage may assist to understand developmental factors linked to less than optimal self-management. This may also assist in the development and implementation of developmental-specific interventions. For example, Grey and colleagues (2002) reported the results of their coping skills intervention with youth initiating flexible diabetes management regimens. Their population ranged in age from 12-

20 years (mean 14.2 years, *SD*=1.9). However, it may be that some interventions would be implemented or designed differently for a 12 year -old (early adolescence) versus a 20 year -old (late adolescence), given that each stage is characterized by its own unique developmental milestones and, as such, presents a different set of risk and protective factors.

Table 2. Stages of Adolescence Reported by Author

| Author | Stages Defined | Source |
|---|---|---|
| Altobelli, Valneti<br>Verrotti, Masedu, Tiberti, Chiarelli, Di Orio (2002) (*Italy*) | 10-14 –Children<br>Adolescents=15-18 | None |
| Dashiff, McCaleb, Cull (2006) | Early 11-15 | None |
| Dashiff (2000) | Early= 10-14<br>Middle=15-17<br>Late 18-20 | Peterson & Leffert, 1995 |
| Hanna and Guthrie (1999) | Early= 12 -14<br>Middle=15-17<br>Late= 18-24 | None |
| Hanna and Guthrie (2001) | Early= 11-13<br>Middle= 14-16<br>Late = 17-18 | None |
| Leaonard, Garwick and Adway (2005) | Middle=14-16 | None |
| Madsen et al. (2002) | Younger=13-15<br>Older=16-18 | None |
| Schilling et al. (2006) | Early=11-15<br>Middle= 15-17<br>Late= 17-19 | Hamburg, 1998 |
| Schmidt (2007) | School=6-10<br>Preadolscent=11-13<br>Adolecents= 14-18 | None |

| | | |
|---|---|---|
| Silverstein et al.<br>American Diabetes Association (ADA) (2005) | Older<br>Elementary= 8-11<br>Early =12-15<br>Late=16-19 | None |

## Adolescent Development

Adolescent development may be conceptualized in terms of cognitive, psychosocial, emotional, physiological and physical (psychomotor maturity) aspects. These areas of development are interrelated, yet remain separate entities. Advanced development in one area does not necessarily mean the adolescent is equally developed in another. Because self-management processes involve labile behaviors that change over time (Harris et al., 2000), the relationship of age and development to self-management is dynamic as individuals move through the life span. Growth and development have an impact on diabetes self-management behaviors that are particularly important in adolescence, a period characterized by rapid physical and cognitive development (Silverstein et al., 2005). It is important to study self-management behaviors across the developmental continuum, as it has been suggested that these behaviors change over time (Harris et al., 2000; Sawyer & Aroni, 2005; Schilling et al., 2006).

### *Cognitive Development*

Research on cognitive development seeks to describe and explain how we think and process information at different points along a developmental continuum (Kimmel & Weiner, 1995). The cognitive process is very important to adolescents with T1D because it has major influence on the ability to problem solve and conceptualize diabetes-related knowledge. Similar to physical growth and development, there are several norms that are often referenced when assessing an adolescent’s cognitive development (Kimmel & Weiner, 1995). Cognitive development normally moves in stages from concrete to abstract thinking. Adolescents usually transition from concrete to abstract thought beginning in early adolescence and continue to further develop these more advanced thought processes into middle and late adolescence (Monasterio, 2002). Concrete thinking is characterized by a “black and white” mentality with clear yes or no, right or wrong thinking; concrete thinkers like rules. Complex decisions that involve critical thinking and a higher level of problem solving are difficult for the concrete thinker. In early adolescence, there is considerable variability in the balance between concrete and emerging abstract thinking in any single adolescent. In some situations, especially those that are new and stressful, concrete thinking is more dominant because it is more familiar, where familiar situations may allow for more practice with the newer abstract form of thinking. Early adolescents may not think ahead to the consequences of their actions in the middle of a novel situation and instead will rely on a set of rules for behavior that may or may not be appropriate. However, most early adolescents are capable of rudimentary abstract thinking with guidance. Table 3 is a general guide to which chronological age and stage may correspond with selected milestones of cognitive development. Noteworthy are the differences between each area of development and the milestones with each.

Table 3. Cognitive and Psychosocial Developmental Milestones

| Age/Stage | Cognitive Development | Age /Stage | Psychosocial Development |
|---|---|---|---|
| Early (12-14) | Begin to think abstractly, think ahead to consequences | Early (10-13) | Initiate struggle for independence, initiation of movement away from family, beginning peer group involvement |
| Middle (15-17) | Understand consequences of actions, develop new thinking skills, less self focused, deductive reasoning | Middle (14-17) | Increased scope and intensity of feelings with more of a focus on peer involvement |
| Late (18-20) | Think abstractly, understand principles and apply them to other situations, thinking about the future | Late (17-21) | Struggle for identity and separation<br>Less focus on peers, more comfortable with own values and identity |

Adapted from: “The well adolescent.” In R.T. Mercer (ed.), By R. Mercer, 1979, *Perspectives on adolescent health care*, Philadelphia: J.B. Lippincott Co. p. 3-28; “Enhancing resilience in the adolescent,” by E.B. Monasterio, 2002, *Nursing clinics of North America.* p. 373-379; “Psychosocial development in normal adolescents,” by L. Neinstien, 1996: *Adolescent Health Care: A Practical Guide 3rd ed.* Baltimore: Williams and Wilkins & “Developmental issues influence guidelines for adolescence health research,” by A.C. Petersen & N. Leffert, 1995, *Journal of Adolescent Health*; 17, 298.

Abstract thinking includes the ability to consider different and multiple perspectives, such as those of others’, as well as considerations for the long term ramifications for the future, and to consider alternatives (Monasterio, 2002). Abstract thinking begins in the later part of early adolescence and continues to develop through middle to late adolescence, but is not well established until late adolescence or young adulthood (Petersen & Leffert, 1995).

Cognitively, the ability to think abstractly and contemplate the future is developing in middle to late adolescence. However, the need for autonomy and social changes often result in diminished self-management during this time (Madsen et al., 2002). Also, the impact of cognition on problem solving is considerable and includes the ability to think logically, to use deductive reasoning, and to consider options.

Unfortunately, there is no specific age when cognitive development changes from concrete to abstract, rather it develops as a gradual process over time. Research has supported a strong correlation between age and higher levels of cognition, with the caveat that measuring cognition can be problematic (Desrocher & Rovert, 2004; Thies & Walsh, 1999). This means that the cognitive process improves as adolescents age as outlined in Table 3. However, when a chronic condition is present, cognitive development may be extended into late adolescence, not because of physiological influences in brain chemistry, but resulting from a generic response to having a chronic condition that is not well understood (Suris, Michaud, Viner & Liu, 2005).

The developing adolescent is more prone than adults to episodes of hypoglycemia and DKA (DCCT, 1993; Travaglini, Garg & Jelley, 1998). Secondary to a lack of ability of brain cells to store glucose, the brain is particularly susceptible to temporary or permanent damage resulting from aberrations in blood glucose levels and results in deficits such as: 1) motor deficits, particularly with an early age diabetes onset, 2) attention and memory deficits, 3) verbal and executive function deficits and, 4) puberty and executive functioning differences (Descrocher & Rovet, 2004). Motor function, attention, memory and executive functions have been shown to be reduced with episodes of hypoglycemia, the degree to which depends on the severity, duration and frequency of the hypoglycemia (Descrocher & Rovet, 2004). Some of the processes influenced by executive functioning include memory (recall), prioritizing, and initiation and follow through with tasks, and analyzing information.

All of these cognitive processes are essential for optimal self-management behavior. Except for episodes of DKA, hyperglycemia is less problematic than hypoglycemia but also has effects on neurocognitive function. Chronic hyperglycemia has been associated with poor visual spatial abilities and difficulty with the inhibitory component of attention (Descrocher & Rovet, 2004). Episodes of DKA can cause central nervous system damage, and the presence of ketones may influence spatial abilities (Descrocher & Rovet, 2004).

The onset of puberty has a significant influence on neurocognitive functioning as hormones present in puberty increase insulin resistance; hence adolescents are particularly vulnerable to aberrant blood glucose levels. In addition, there may be a correlation between neurocognitive functioning and the onset of puberty. Desrocher and Rovet (2004) demonstrated executive function deficits in adolescents with T1D regardless of the age of diabetes onset, suggesting that certain deficits in cognitive function appear after puberty. It has been demonstrated that the higher levels of executive functioning necessary to problem-solve, self-monitor and utilize working memory (all skills that are important to self-management) are related to higher levels of regimen adherence, regardless of age (Bagner, Williams, Geffken, Silverstein & Storch, 2007). Deficits in executive functioning can be detrimental to successful self-management.

### *Psychosocial Development*

The intrusive nature of diabetes self-management may be in direct contrast to the psychosocial developmental tasks of adolescence: to gain autonomy, independence and establish relationships with peers. Adolescents may not have the developmental readiness to assume the majority of their self-management responsibility, which can be problematic as they spend more time with peers away from home (Miller & Drotar, 2007). The role of social and peer influence, coupled with the desire to fit in may be a higher priority than practicing optimal self-management.

Psychosocial development is variable and does not occur in a linear trajectory. It is typical for adolescents to undergo periods of regression and acceleration within the adolescent period of development (Neinstein, 1996). As adolescents move from pre to early adolescence there is an emotional separation from parents and a strong peer influence (Christie &Viner, 2005). Also, by the end of adolescence, most have achieved a degree of independence from parents and have adopted a social identity from which to begin their adulthood (Suris, et al., 2005). Each stage of adolescence can be characterized by some general developmental tasks. Table 3 displays some of the important psychosocial milestones and the age at which they may occur, which is of great importance as adolescents transition into more independent self-management.

During early adolescence, as early as age 10, there is significant movement toward the peer group (Neinstein, Juliani & Shapiro, 1996). The degree to which adolescents with diabetes are supported by their peers may directly influence their self-management. In their literature review, Wysocki and Greco (2006) reported that social support from peers positively affected lifestyle aspects of treatment regimens in children and adolescents with diabetes. Those youth with diabetes experienced more ease with self-management of their regimens when supported by peers than those who did not perceive support from peers. Wysocki and Greco (2006) also reported that interventions aimed at increasing positive, helpful behaviors from peers toward youth with diabetes improved adolescents' self-management of diabetes. This is important given that children and early adolescents tend to think concretely and may not consider the consequences of managing their diabetes when with peer groups. As such, they are more apt to do the right thing according to pre-determined rules. However, if they receive negative feedback or a lack of support from peer groups, their behaviors may change so as not to be different. This change during middle to late adolescence with the development of the ability to think beyond rules and consider “what if” peers gave negative feedback about their diabetes self-management or found out they were different. Also during this time, the peer influence increases and the consequence of managing diabetes in the presence of peers may have undesired social consequences. Some studies reported negative consequences such as “standing out” (Williams, 1999) or being bullied (Storch et al., 2006) when adolescents perform diabetes self-management tasks. Negative consequences such as these may cause adolescents to choose to avoid good self-management practices.

### *Emotional Development*

By the end of childhood and the beginning of adolescence, youth have developed the ability to better regulate the expression of their emotions (Zeman, 2003). There are three major influences on adolescent emotional growth: cognitive development, hormonal changes and life events (Rosenblum & Lewis, 2003). Receiving a diagnosis of diabetes, a major chronic illness with significant lifestyle changes, represents a major life event during an already complicated period of life. Although adolescents' ability to regulate their emotions is developed, it is impacted significantly by their heightened sense of how others evaluate them. Child psychology and education expert, David Elkind (1998), has described this heightened sense of others as if an adolescent were performing on stage, where the social structure of his or her peers and significant adults are the audiences. The emotional expressiveness of the adolescent is based on obtaining approval from the audience. This has translated into the notion that adolescents frequently feel as if every detail of their lives is observed and evaluated by others. Because T1D is a condition that requires frequent actions (e.g. blood glucose monitoring [BGM]) that are readily observable, this has implications for self-management, as those tasks that are observable by peers may be avoided (Storch et al., 2006).

As expected, emotional development is also affected by gender, which may have some implications for the gendered meaning of diabetes. For example, in her qualitative descriptive study of adolescents ages 15-18-years of age, Williams (1999) showed a difference between males and females in how they lived with their diabetes. The types of emotions displayed by females were more likely than males to include those that denoted vulnerability (e.g. fear, stress), because males believed they would receive less understanding from peers or adults about expressing these emotions. The decision to regulate emotions more strictly in the presence of certain social groups is a conscious one based on the expectation of how the emotion will be evaluated by others (Zeeman, 2003). Furthermore, females develop on an average of 1.5 to 2 years ahead of males (Peterson & Leffert, 1995). Thus, it is important to understand gender differences across adolescent stages. Placing a range on the ages will help account for some of the developmental differences inherent between gender groups.

### *Physiological Development*

The onset of puberty during early adolescence, combined with rapid physiological growth, causes the need for frequent insulin adjustment (Golden, 1999) and is characterized by a 25-30% lower response to insulin (insulin resistance) (Brink, 1997; Golden, 1999; Halvorson, Yasuda, Carpenter & Kaiserman, 2005). Hence, at a time when youth are becoming more engaged in self-management, they are experiencing physiological changes that complicate their regimen. A common measure of successful self-management is glycocylated hemoglobin (HbA1c), glucose attached to hemoglobin which gives an index of average blood glucose for the previous three months. Because of physiological variations during puberty, researchers, clinicians, parents and adolescents must view the HbA1c with consideration to physiological growth and development. Even the best self-management practices may not result in optimal physiological control (Brink, 1997; Springer et al., 2006), which can be discouraging for adolescents. It is particularly important for clinicians and parents to understand and continue to encourage teens to strive for optimal self-management behaviors so they maintain as much control as possible.

### *Physical/Psychomotor Development*

The psychomotor skill capacity to perform many of the technical tasks required for diabetes self-management (e.g. insulin pump programming, insulin injection, glucose monitoring) begins in early school age and is well developed by early adolescence (ADA, 2005; Halvorson et al., 2005). However, apparent mastery of psychomotor skills should not be confused with the ability to apply all the principles of self-management. example, an adolescent, because of his/her ease at manipulating high technology devices, might be given complete responsibility of programming the insulin pump without parental supervision or oversight. This adolescent may not pay attention to detail and make a computational mistake regarding the insulin dose (Halvorson et al., 2005) or may not administer the correct insulin dose. Therefore, while adolescents may demonstrate skills and knowledge necessary to perform their diabetes activities by early adolescence, (ADA, 2005; Sawyer & Aroni, 2005), they may lack the cognitive skills to successfully self-manage without supervision and/ or consultation.

## Self-Management

Diabetes is primarily self-managed by adolescents in conjunction with their health care providers and parents. However, there is neither conceptual agreement nor a uniform definition of self-management available in the literature (Harris et al., 2000; Lorig & Holman, 2003; Schilling et al., 2002), and it means different things to different people (Sawyer & Aroni, 2005). Although the lack of conceptual clarity exists in many of the studies in the extant literature, it is especially problematic when reviewing studies from different countries where language and cultural influences make it difficult to determine if the study is actually about self-management or a related construct. For example, Altobelli et al., (2000) (Italy) used self-monitoring to describe and measure family and disease management in youth with T1D, < 14 years of age, and later report results by using the term compliance.

Some of the terms that are frequently used interchangeably with self-management are compliance and adherence. Compliance was a term that came into use in the late 1970s to reflect the extent to which a person’s behavior coincided with medical advice (Haynes, Taylor & Sackett, 1979). However, there has been controversy surrounding the term because it was thought to be paternalistic in nature (Lutfey & Wishner, 1999).

In the 1990s, the term adherence came into use as an alternative term which has been used to describe the degree to which the patient follows their care provider’s advise regarding their medical regimen. It is implied that patients have more autonomy in defining and following their medical regimen (Lutfey & Wishner, 1999). Dr. Dennis Drotar, a professor in the Division of Behavioral Medicine and Clinical Psychology and director of the Center for Adherence and Self-Management at Children’s Cincinatti (2009) differentiates adherence from self-management by defining adherence as following the prescribed regimen and self-management as managing treatments at home.

In their concept analysis Schilling and colleagues (2002) described self-management in youth as a more encompassing concept that includes following the medical regimen but also includes collaboration with parents/health care providers and setting diabetes-related goals. Conceptual clarity is essential to understand what behaviors are being measured in empirical work and to synthesize literature to understand self-management behaviors. This will be increasingly important as correlational and descriptive studies that describe self-management behaviors lay the foundation for intervention research. Without a conceptually congruent in-depth understanding of the attributes of self-management, it will be very problematic to measure and hence understand and manipulate self-management behaviors in future studies.

Schilling, Grey and Knafl (2002) have conceptualized self-management as having three essential attributes: (1) an active and proactive process (e.g. collaboration with parents and health care providers), (2) activities (e.g. blood glucose monitoring and insulin administration) and (3) Goals (e.g. target glucose levels, HbA1c). These attributes capture the complexities of managing a chronic disease as difficult and multi-faceted as diabetes. This paper suggested a working definition of self-management as an … "active, daily, and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness related activities" (Schilling et al., 2002, p. 92). This definition has been revised to include collaboration with health care providers (HCP) L. Schilling (personal communication, August 10, 2008). Those studies that did include one or all of the essential attributes of self-management (process, activities, and goals) were included in this review.

## Variables Under Investigation

### *Collaboration with Parents*

The age at which diabetes care activities should transfer to the adolescent from the parent will vary and should be based on development and maturity (Guthrie, Bartsocas, Chabot & Konstantinova, 2003). Metabolic control, albeit difficult to maintain in adolescence, is more likely to be compromised in those who are given complete autonomy of their diabetes care activities without the developmental maturity to do so (Wiebe et al., 2005; LaGreca, 1998). However, the most common motivation reported by parents to transition adolescent diabetes care activities was typically the adolescent's chronological age (Palmer et al., 2004). Schmidt's (2007) study of 88 mothers of children and adolescents with diabetes, converted her sample into three levels: school age (6-10 years), preadolescent (11-13 years) or adolescent (14-18 years). One of the aims in her study was to determine if there were relationships between a child's chronological age, mother's perceptions of the child's diabetes abilities and adolescent self-reported self-care tasks. The scale used in the study was developed by Schmidt but she reported only the subscale alpha reliabilities. Cronbach's alpha for the self-care activities subscale was good at 0.88. For the 14-18 year old group, the results showed a significant positive relationship between mother's perceptions of self care activities scores and the teens self-reported independent self-care tasks, ($r$=0.62, $p$=0.000). This suggests that there is a relationship between what youth report they do and the mother's reports of what they do which may translate to mother's perception of youth to be capable of independent self-care.

In their qualitative study, Schilling, Knafl and Grey (2006) described the division of labor and transfer of responsibility to be transitional in early adolescence (11-14 years), mostly adolescent-dominant in middle adolescence (15-16 years) and adolescent- dominant by late adolescence (17-19 years). These findings suggested that the transfer of responsibility for self-management during adolescence was mostly completed by the time late adolescence begins. Table 4 summarizes these findings.

Table 4. Division of Labor and Transfer of Responsibility by Stage of Adolescence

| Stage and Age Group | Division of Labor | Transfer of Responsibility |
|---|---|---|
| Pre Adolescent | Parents perform much of diabetes care | Parent-dominant self-management |
| Early (11-15) | Adolescent performs much of diabetes care | Transitional self-management |
| Middle (15-17) | Adolescent performs most of diabetes care | Adolescent-dominant for some, transitional for others |
| Late (17-19) | Adolescent performs all of diabetes care independently with frequent parental reminders | Adolescent-dominant |

Adapted From “Changing patterns of self-management in youth with type 1 diabetes,” by L.S Schilling, K.A. Knafl & M. Grey, 2006, The Journal of Advanced Nursing, 37, p. 415-416.

Parent involvement in diabetes management must be balanced with the developmental level of the adolescent (Hanna & Guthrie, 2001). For instance, data suggest that too much or too little involvement can be deleterious to adolescent self-management behaviors and metabolic control (Wiebe et al., 2008). Further, balance is required as a means of encouraging self-management; if parents are over-involved, they do not allow adolescents to develop competence as autonomous persons. If parents are under involved it may compromise metabolic control (Hanna & Guthrie, 2001). Hanna and Guthrie (2001) demonstrated that adolescents aged 11-18 years perceived personal responsibility of self-management to be burdensome, and activities that were considered burdensome may be avoided by adolescents. Findings from several studies highlighted the importance of shared responsibility (teamwork) for diabetes self-care through early to middle adolescence (Anderson, Brackett & Laffel, 1999; Helgeson et al., 2007) with a gradual transition to adolescent independent decision-making in late adolescence and adulthood (Hanna & Guthrie, 2003). Further, both the clinical practice guidelines (ADA, 2008) and the *Care of Children and Adolescents with Type 1 Diabetes Statement* (ADA, 2005) illustrate the necessity of always having an adult to assist with diabetes self-management. Among other things, these recommendations are in place because of the  possibility of impaired thinking/functioning secondary to hypoglycemia or hyperglycemia in diabetes, even in adults with T1D.

Leonard, Garwick and Adway's (2005) qualitative descriptive study of 18 adolescents (14-16 years) reported teens with higher HbA1cs described collaboration with parents as annoying, where those with lower HbA1cs described positive collaboration and better adherence.  It is important to understand and consider adolescent development when deciding to reduce parental collaboration to a mostly consultative in adolescent diabetes care activities.  Developmental considerations can then be used to develop age-targeted transitional care interventions to help with the gradual transfer of care from parent to adolescent.

### *Diabetes Care Activities*

Diabetes care activities range from simple to complex and constitute one of the essential attributes of self-management (Schilling et al., 2002).  Descriptions of what constitutes diabetes care activities in the literature vary, but most include insulin administration (including adjustment), regulating diet, exercise, BGM, urine testing and responding to hypo and hyperglycemia (Schilling et al., 2002). It has been recognized that the fine motor skills and competency to perform simple activities such as insulin injections, BGM and insulin bolus (CSII) can be mastered as early as the school-age years (ADA, 2005, Schmidt, 2007).  As displayed in Table 4, Schilling et al., (2006) reported that by early adolescence most participants in this qualitative study were administering their own injections and boluses and performing BGM during the day, although some adolescents still had their parents perform nighttime BGM.  It is also during this early stage of adolescence that adolescents begin to assume responsibility for food choices (dietary management), an activity that has been associated with better adherence and glycemic control (Mehta et al., 2008; Schmidt, 2007; Skinner & Hampson, 2001). Nonetheless, most authors suggest that although most of the more simple diabetes care activities should be performed by youth in early adolescence, those that require higher cognitive processing and are complex (e.g. insulin adjustments) should be supervised by a parent until late adolescence (ADA, 2005). However, results from Schilling and colleagues' (2006) qualitative study suggested that this may not be happening.

### *Diabetes Problem Solving*

Problem solving for an adolescent with diabetes is a decision-making process that goes beyond knowledge and skill. It includes an evaluation of outcomes and it involves adjusting the diabetes management regimen. Adolescents must take into consideration many variables when adjusting their regimen such as: HbA1c goals, blood glucose levels, exercise (actual and anticipated), dietary intake (type of food as well as amount and time), regimen type and self-management goals (American Association of Diabetes Educators [AADE], 2005, Schilling et al., 2002). Essential components of problem solving in self-management have been described as: (1) problem solving skill, (2) problem solving orientation, (3) disease specific knowledge and, (4) transfer of past experience (Cook, Aikens, Berry & McNabb, 2001; Hill-Briggs, 2003). In other words, problem solving involves combining the synthesis of knowledge and past experiences with an application of skills into a behavior (Hill-Briggs, 2003).

During early adolescence, problem solving can be difficult because some adolescents are still concrete thinkers, while others can use more logic and abstract thinking methods (Kimmel & Weiner, 1995). A major milestone during early adolescence is the ability to consider the effects of immediate decisions on future outcomes (Kimmel & Weiner, 1995). The ability to think hypothetically along multiple dimensions combined with greater selfreflection creates a context for knowledge and represents key elements of problem solving (Cook et al., 2001).

Throughout middle adolescence the ability to problem solve is directly related to the capacity to combine abstract reasoning and logical thinking. These processes are about as well developed as in adulthood during this stage (Petersen & Leffert, 1995). However, adolescent behavior does not always corroborate this fact, because there are other variables that influence problem solving, such as the ability to consistently transfer information from past experience and knowledge (diabetes-related) (Kimmel & Weiner, 1995). Although adolescents can apply broad principles to situations, their lack of experience and disease-specific knowledge may not be similar to that of an adult, so it is more difficult to transfer knowledge and past experience to a current situation. Hence, early and middle adolescents may be missing these essential components of problem solving (Cook et al., 2001).

Cognitive processes during late adolescence move significantly toward thinking more abstractly, and individuals in this age group are able to solve problems more quickly. With longer duration of illness, adolescents may have had more diabetes management experiences and overall diabetes knowledge that they can apply to helping them better problem solve diabetes issues. A major milestone during late adolescence is the development of goals and a movement toward the future.

There are currently three problem solving measures for children/adolescents and eight published studies in the extant literature (Hills-Briggs & Gemmell, 2007). The means by which problem solving is measured are often (1) process measures to assess cognitive and behavioral processes to develop solutions or (2) outcome measures to assess the quality of the solution (Cook et al., 2001). In Ingersoll, Orr, Herrold and Golden’s 1986 study (as cited in Golden, 1999) they reported that more complex cognitive process in adolescents is related to improved metabolic control. Cook and colleagues (2001) found the correlation between problem solving and adherence measures to be stronger (*r*=0.40, *p*<.01) than problem solving and metabolic control (*r*=-0.28, *p* <.05). Data from most studies indicate only a modest 25% of problem solving interventions result in an improvement in HbA1c (Cook et al., 2001). This discrepancy is likely reflective of the fact that it is problematic to measure problem solving strictly by metabolic control (HbA1c), as there are other variables that affect metabolic control. Further, a higher cognitive process may result in a higher order of problem solving, but not necessarily assure the application of that knowledge. In other words, an adolescent who is capable of independent problem solving does not always make the best decision. Reasons for this are numerous and may include psychosocial factors and/or communication problems.

### *Diabetes Communication*

Communication means more than language development and includes the way in which we send and receive information, including assigning meaning to information (Fitzpatrick, 2004). As adolescents develop cognitively, so too does their ability to send and receive communication. Clinicians and parents must use developmentally appropriate communication skills with adolescents to avoid miscommunication (Fitzpatrick, 2004). Most studies have reported that negative communication has a detrimental influence on diabetes self-management while, conversely, positive communication produces a positive effect on self-management behaviors (Dashiff, Hardeman & Mc Lain, 2008). Adolescents communicate about their diabetes with parents, teachers, employers, health care providers (HCP) and friends, and it is unclear how this changes across adolescence.

Communication is an integral part of self-management, especially as adolescents negotiate responsibilities with their parents as well as with HCPs. In their integrative review, Dashiff and colleagues (2008) suggested that supportive communication in regard to diabetes management was important to achieve positive diabetes-related outcomes. Their meta analysis supported the finding that communication that was perceived as negative, controlling or nagging resulted in increased parent-adolescent conflict. Conflict is inevitable, and communication is a key component to negotiating and resolving conflict. Miller and Drotar (2007) reported that negative communication contributed to conflict and had a negative impact on self-management. Negative parent-adolescent communication was associated with higher HbA1c values ($r$=-.29, $p$ <.03), parent report of lower compliance ($r$=-.28, $p$ <.03) and lower provider reports of adherence ($r$=-.26, $p$ <.04) (Miller & Drotar, 2007).

Laursen, Coy and Collins (1998) reported results from their meta analysis that debunked what they thought to be traditional views of a curvilinear relationship of conflict in adolescence. Instead of an increase in conflict during early adolescence, stability during middle adolescence, and a decline in late adolescence, they suggested a linear decline in conflict rate from early to middle to late adolescence. This suggests an inverse relationship with communication and conflict; as communication becomes more effective, conflict frequency decreases. However, conflict can be measured by affect (intensity) or frequency (rate). Interestingly, early to middle adolescence is a time where conflict affect increases although it is not necessarily more frequent (Hanna, Juarez, Lenss & Guthrie, 2003; Laursen, et al.,1998).

Effective communication with adults other than parents is important as well. Adolescents who receive supportive communication from teachers and HCPs will practice better self-management (Hains et al., 2006; Kyngas, Hentiman & Barlow, 1998). Ginsberg and colleagues (2005) noted that HCPs are in a particularly good position to communicate with adolescents because of adolescents' desire to gain independence from their parents. HCPs are adults who can guide self-management, while supporting adolescents to reach the developmental goal of independence from their parents. However, adolescent egocentrism may create barriers between adolescents and their HCPs (Madsen, Rolsman & Collins, 2002).

Adolescents are developing their own self-identity, and when combined with cognitive development, they may make their own decisions regarding their diabetes management (Madsen, Roslman & Collins, 2002). Barriers between HCP's and adolescents can be overcome by developmentally appropriate care, thus highlighting the need for providers to consider development when treating adolescents with T1D (Hood & Nansel, 2007).

In their qualitative study, Kyngas, Hentiman and Barlow (1998) conducted a study to examine how adolescents with T1D perceived the actions of the physicians. They reported adolescents (13-17 years) who perceived attributes of effective communication from HCPs (such as asking questions, listening to and respecting their opinion as the patient) practiced better compliance. Compliance in this study was measured by a questionnaire which covered insulin treatment, diet, home monitoring and co-operation with health care staff. Although the authors note the questionnaire to be both valid and reliable, no statistics were given to support this claim.

Descriptive studies suggest that adolescents communicate with friends about having diabetes but have adherence difficulties when they were concerned with their friends' reactions to self-care activities (Hains et al., 2006; Kyngas, Hentimen & Barlow, 1998; Storch et al., 2006). Those adolescents who viewed friends' communication as supportive (e.g. adjusted to the diabetic's lifestyle, reminded them about self-care) had better compliance (Hains et al., 2006; Kyngas et al., 1998). As identification with peers increases during middle adolescence, this may correspond with a decline in diabetes-related communication during this period (Christie & Viner, 2005). During late adolescence, social autonomy develops, and this may correspond with an increase in communication with friends about diabetes during this period. No studies reviewed for this paper described the characteristics of communication with parents, HCPs or friends by stage of adolescence so we can only speculate about the influence of communication during adolescence.

### *Goals*

There are two general types of diabetes-related goals adolescents may participate in: treatment and diabetes self-management goals. Some diabetes treatment goals may include target blood sugar and HbA1c values. Diabetes self-management goals may include: managing diabetes more independently, avoiding present and future complications from poorly controlled blood glucose levels, participating in normal adolescent social activities, and the ability to participate in more activities with friends, such as staying overnight away from home (Schilling et al., 2002). Grey, Davidson, Boland and Tamborlane (2001) demonstrated that coping skills training may help adolescents (12-20 years) to achieve treatment goals aimed at improving quality of life and metabolic control, but they did not report age-related differences in goal attainment or individual self-management goals. The degree to which the adolescent has endorsed any diabetes-related goal(s), if at all, may have a significant impact on the behaviors designed to meet these goals. Developmentally, it would seem that in middle adolescence the progression of movement toward independence and abstract thinking would result in increased diabetes-related goal setting. Goals during the late adolescent period would be developmentally appropriate, such as self-managing their diabetes in order to spend more time away from home with peers. However, what goals are set throughout the stages of adolescence remains unstudied.

## Risk and Protective Factors

Health status and individual factors often influence diabetes self-management behaviors and can serve as either risk or protective factors (Knafl, Grey & McCorkle, 2006). The uniqueness and complexities of self management are influenced by many things including. The medical regimen followed, duration of illness and gender. However, there are few studies, to date, with a focus on regimen and duration of illness. Although the affect gender has on self-management has been widely studied, the findings from studies are conflicting. Therefore it is unclear if regimen, duration of illness and gender are potential risk or protective factors for optimal diabetes self-management. Further, no reports have investigated these factors across stages of adolescence. Therefore, in this study I have investigated the influence of medical regimen, duration of illness (trajectory) as well as gender (an individual factor) across stage of adolescence.

## Health Status Factors

### *Regimen*

Activities associated with a specific diabetes treatment regimen can be somewhat complicated (e.g. checking blood glucose three times daily and twice daily injection of a consistent dose of insulin) or very complicated (e.g. checking blood glucose levels six to eight times and computing multiple doses of insulin every day). Certainly the process of daily disruption, degree of difficulty and the burden self-management activities can place on an individual cannot be disregarded.

It is unclear if regimen serves as protective or risk factor or both. In some regard, flexible regimens may be protective because they offer more flexibility with meal time, dietary choices and exercise, and offer better metabolic control. However, flexible regimens may also pose a risk factor for optimal self-management given the intrusive nature of the tasks associated with this regimen. In fact, it has been suggested that regimens may be chosen based on the ability to decrease school time diabetes care activities (Williams, 1999). These findings suggest that those behaviors that are observable by nature are more likely to be neglected or avoided. Data also indicate that adolescents neglect activities perceived as burdensome (Hanna & Guthrie, 2000) or that must be done at specific times (Streisand et al., 2002).

Conventional regimens too, are anything but simple. They offer less flexibility and require timed meals and snacks to offset insulin peaks, with the need to increase carbohydrate intake to offset exercise. They do not offer the same opportunity for optimal metabolic control when compared to flexible regimens (DCCT, 1993). However, they offer less burdensome self-management behaviors (e.g. decreased frequency of insulin administration and blood glucose monitoring), and some of the associated tasks (e.g. insulin administration) may be avoidable in social settings (school). Whether these regimens function as risk or protective factors in self-management of T1D in adolescents and whether this depends on the developmental level of the adolescent, remains unstudied.

How regimen influences self-management behavior is especially pertinent given the recommendations from the ADA (2005) that children greater than age 7 years be on flexible as opposed to conventional regimens. Most regimen-related studies have been cross-sectional and reported correlations between metabolic control and regimen rather than between regimen and self-management. Springer et al. (2006) reported in a large study ($N$=455) that injection (vs. pump regimen) therapy was significantly ($r$=0.19, $p$<.001) associated with higher HbA1c levels. However, injection therapy does not necessarily mean a conventional regimen because flexible regimens can be accomplished with multiple daily injections as well. Findings published from the adolescent cohort in the DCCT (1994) had mean HbA1c levels that were significantly ($p$<.0001) lower with intensive therapy (8.06%) than conventional therapy (9.7%). What is not clear is whether regimen directly affects metabolic control or does so by influencing self-management. Therefore, it remains unknown if flexible regimen is a potential risk or protective factor in self-management, and if the effect of regimen is static across adolescence.

Social pressures and peer influence, coupled with the desire to fit in, may be a higher priority than performing the constant diabetes care tasks associated with self-management, especially with flexible regimens. Storch et al. (2006) examined 167 youth (8 to 17 years) and reported that diabetes-related bullying was significantly and negatively correlated with overall self-management activity (*r*= -.30, *p*<.001), indicating more bullying meant less optimal self-management. They also reported that diabetes-related bullying significantly predicted 9% (*p* < .001) of the variance in self-management activity. Specifically, significant negative correlations were found between bullying and the self-management activities of BGM (*r*=-.27, *p*< .001) and dietary modifications (*r*=-.27, *p*< .001), and the authors suggested that these tasks may be avoided in social settings (e.g. school). Interestingly, there was no correlation between bullying and the activity of insulin administration (*r*= -.13, NS). Although the regimen type (flexible or conventional ) was not reported for the sample, insulin pump therapy was an exclusion criterion in order to maintain homogeneity in the sample. The lack of significant results may be due to the children in the study being on conventional regimens. It is possible that insulin administration did not occur in school and therefore would not be an observable behavior subject to bullying.

### *Duration of Illness (Trajectory)*

Trajectory refers to the various stages an individual with T1D, or any other chronic illness, goes through based on physical and psychosocial consequences of a condition (Grey, et al., 2006). These stages are dynamic and fluid as periods of exacerbation lead to more unstable phases characterized by a reevaluation of self-management goals and activities, as well as the impact the illness has on daily living (Grey et al., 2006). Loring and Holman (2003) pointed out a paradigm shift that occurs as a direct result of patient perspectives of their condition in a chronic illness. They suggested self-management behaviors may assist in maintaining a focus on wellness rather than illness. How adolescents view their diabetes may have a lasting impact on their adult perspective of the disease (Aroni & Sawyer, 2005). Trajectory adjustment and management of diabetes in adolescence is thought to be a predictor of future adherence and health care utilization (Wysocki, Taylor, Hough, Linscheid, Yeates & Nagleiri, 1996), Trajectory also may influence individual beliefs about diabetes and treatment (Hampson et al., 2001).

As illustrated in Table 5, trajectory is often studied as duration of illness (DOI) and is measured by chronological length of time since diagnosis (e.g. 6 years, 3 months). Because the relationship between health status factors and self-management is likely variable and differ between individuals and the condition (e.g. cystic fibrosis, T1D) chronological measurement is problematic. What makes measuring trajectory by chronological age even more problematic in the case of diabetes are the differing ages of diagnosis. The literature has supported a decline in self-management practices as adolescents age (Springer et al., 2006), but did not necessarily control for age at diagnosis (e.g. a 15 year old that was diagnosed at age 2 verses age 13). Several studies demonstrated higher HbA1c as youth aged, suggesting a positive correlation between DOI and self-management in adolescence (Dashiff, McCaleb & Cull, 2006; Hanna & Guthrie, 1999; Helgeson, Reynolds, Escobar, Siminerio & Becker, 2007; Springer et al., 2006). Only one study, (Streisand et al., 2002), reported a negative association between DOI and the dietary management ($r$= -.52, $p$ <.05) and BGM ($r$= -.57, $p$ <.05), suggesting that a longer duration of illness is associated with higher BGM and eating frequencies. Another study (Faulkner & Chang, 2007) reported that duration of illness was not a significant predictor of self-management as measured by the self-care questionnaire. Therefore, it is not clear if there is a decline in self-management as DOI increases, or if this is secondary to advancing age or both. To date, no studies have explored DOI as a potential risk or protective factor, specifically by stage of adolescence. As adolescents continue to face the typical challenges of this life stage, they are also faced with living with their condition. It is important to better understand at what point in diagnosis self-management practices may decline in order to place interventions to support treatment and individual goals at appropriate chronological time points after diagnosis.

Table 5. Relationship of Regimen and Duration of Illness to Self-Management

| Author | Title | Design | Variable | *N* | Age | Measures | Results |
|---|---|---|---|---|---|---|---|
| Faulkner & Chang (2007) | Family influence on self-care, quality of life and adolescents with T1D | Descriptive correlation | DOI | 99 | 10-18 years | Self-Care Quest-ionaire | DOI not significant predictor of self-management |
| Hanna & Guthrie (2000) | Adolescents perceived benefits and barrier related to diabetes self-management-Part I. | Qualitative Description | Regimen | 16 | 11-18 years | none | Activities perceived as burdensome were considered to be a barrier to self-management. |
| Skinner & Hampson (2001) | Personal models of diabetes in relation to self-care, well-being, and glycemic control: A prospective study in adolescence. | Correlation Descriptive | Regimen | 54 | 12-18 years | Diabetes Self-Care Schedule | Perceived effectiveness of the treatment regimen to control diabetes predicted better dietary self-care. |
| Springer, Dzura, Tamborlane, Steffen, Ahern, Vincent, Weinzimer (2006) | Optimal control of type 1 diabetes mellitus in youth receiving flexible treatment | Retro-spective Descriptive Correlation | DOI<br>Regimen | 455 | <18 years mean 11.8 years | HbA1c for glycemic control (no self-manage-ment measures) | Longer duration of illness is associated with higher HbA1c levels. Injection therapy associated with worse metabolic control. |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| StreissandRespess, Overstreet-Gonzalez de Pijem, Chen & Holmes (2002) | Self-care behaviors in children with T1D living in Puerto Rico | Descriptive Correlation | DOI | 41 | 12.6 years (mean) | 24 hour recall interview Measures poorly described | Longer illness duration was associated with better self care behaviors. |
| Storch, Heiderken,Geffke, Lewin, Ohleyer, Freddo & Silver-stein (2006) | Bullying, regimen self-management and metabolic control in youth with type 1 diabetes | Descriptive Correlation | Regimen | 167 | 8-17 years | Diabetes Self-Manage-ment Profile (DSMP) | Those regimen-related behaviors noticed are often skipped (specifically diet and blood glucose monitoring) |

## Individual Factors

### *Gender*

The influence of gender as a risk or protective factor on diabetes self-management remains unclear. There are conflicting reports in the literature regarding whether males or females are more inclined to practice optimal self-management behaviors. Interestingly, as displayed in Table 6, some studies reported females having better self-management than males (Dashiff et al., 2006; Naar-King, Idolski, Ellis, Frey & Templin, 2006; Streisand et al., 2002). Still others report no difference in self-management behaviors between males and females (LaGgreca et al., 1995), some after controlling for confounding variables such as warmth and caring (Faulkner & Chang, 2007), socioeconomic status (Springer, 2006) and self-reliance (Mansfield et al., 2004). Prior studies have shown that gender was associated with differences in metabolic control in adolescents, with females having worse control than males (LaGreca et al., 1995; Skinner & Hampson, 2001; Springer et al., 2006; Storch et al., 2006).

Naar-King and colleagues (2006) reported in a study of urban youth 10-16 years old, that males had worse regimen adherence as measured by the Diabetes Self-Management Scale (Frey & Denyes, 1989) than females, $t(115)= 2.05$, $p < .01$), but there was no significant difference in HbA1c levels. They suggested that the difference in adherence is partially due to externalizing symptoms of diabetes-related mental health symptoms (i.e. aggression, conduct problems), that were found to be greater in boys by both parent report, $t(115)=-3.41$, $p <.01$) and self-report, $t(108.35)= -3.72$, $p <.05$). Thus mental health factors may be as important a predictor as gender in regards to overall self-management behaviors.

Poor glycemic control among females may partially be explained by the reported increased incidence of diabetes *mis*management, behaviors pervasive in the female population (eating disorders and insulin omission) (Ackard et al., 2008; Cohn et al., 1997; Hanna & Guthrie, 1999; Hanna & Guthrie, 2001; LaGreca, Swales, Klemp, Madigan & Skyler, 1995). What has been clear is that even with Tanner matched males and females, there is an increase in DKA, hospitalizations and eating disorders in the female population (Neurmark-Sztainer et al, 2002). One study of 143 adolescents reported as many as 10.3 % of females compared to 1.4 % of males skipped insulin, and 7.4 % of females used less insulin (1.5% male) to control weight (Neurmark-Sztainer et al., 2002). However, it is not clear at which stage of adolescence these potentially dangerous behaviors are most prevalent. Understanding the nuances of gender and self-management by stage of adolescence is essential so that gender-specific interventions can be developed and targeted at key times.

There are other studies to suggest that there are differences in the *way* males and females conduct self-management behaviors. There may be some gender-related influences on parental collaboration. For example, Williams (1999) conducted a qualitative descriptive study that focused on the gendered meaning of diabetes. Her analysis supported females as being more open with peers about their diabetes and performance of self-care activities, while males refrained from telling others about their diabetes and,as such, were less overt with self-management behaviors. The male participants shared that they avoided flexible regimens because it required performing self-care tasks in social settings (Williams, 1999). This finding was not corroborated in Dickinson & O'Reilly's (2004) phenomenological study that showed that females (*N*=10) did not want to stand out or be watched while doing their diabetes care activities, indicating that females did not want to stand out either.

There may be a difference between when males and females are expected to be independent in their self-management practices. Williams (1999) found that females age 15-18 years were expected to be more responsible for self-management and had less corroboration with their mothers than males. Females in this study also reported being reluctant to ask for help from parents and perceived a high expectation to be independent in the diabetes self-management. Schmidt (2007) reported that mothers' report of the age at which females were independent in self-management BGM was significantly (*p*= .036) different from males (M= 9.18 years for males, M=8.10 years for females). Similarly, the mean age at which females drew up insulin was significantly (*p*=.041) earlier in females (M=10.73) than males (M=10.0). Additionally, Schmidt's findings support mothers' reports of females having significantly (*p*=.023, no other statistic reported) more difficulty than males with dietary adherence. Table 6 summarizes studies gender related studies.

Table 6. Gender, Diabetes Self-Management and Metabolic Control

| Author | Title | Design | Variable | N | Age | Measure | Results |
|---|---|---|---|---|---|---|---|
| Dashiff, McCaleb, Cull (2006) | Self-care of young adolescent with TID | Cross Sectional | Age<br>Gender | 152 | 11-15 years | Self-care adherence inventory (SCAI) | Health deviation self-care decreases with age.<br>Females have better self care |
| Dickson, & O'Reilly (2004) | The lived experience of adolescent females with T1D | Phenomenology | Gender | 10 female | 16-17 years | Qualitative | 5 themes:<br>1-Bending with adolescent culture<br>2-Standing out/ being watched<br>3-Weighing options/making choices<br>4-Being tethered to the system and diabetes<br>5-Struggling with conflicts |
| Faulkner & Chang (2007) | Family influence on self-care, quality of life and adolescents with T1D | Descriptive correlation | Gender | 99 | 10-18 years | Self-Care Questionnaire | Gender not significant predictor of self-management. |
| LaGreca, Swales, Klemp, Madigan & Skyler (1995) | Adolescent with diabetes: Gender Difference in Psychosocial functioning and control | Descriptive Correlation | Gender | 42 | 12-18 years | Self-care Inventory (SCI) | Females had worse metabolic control than males but no differences in self-care. No significant correlation between self-care and metabolic control |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Naar-King, Idolski, Ellis, Frey & Templin (2006) | Gender differences in adherence and metabolic control in urban youth w/poorly controlled Type 1 Diabetes: The Role of Mental Health Symptoms | Descriptive Correlation | Gender | 119 | 10-16 years | Diabetes Self Management Scale (DSMS) | Males had worse adherence than females.<br>No differences in metabolic control. |
| Schmidt (2007) | Self-care in children with T1D A survey of mother | Descriptive Correlation | Gender | 88 | 6-18 years | Researcher Developed Self Care (.88 )& Dietary (.80) | Females more independent in self-care and had more difficulty with dietary adherence. |
| Skinner & Hampson (2001) | Personal models of diabetes in relation to self-care, well-being, andglycemic control: prospective study in adolescence. | Prospective Descriptive Correlation | Gender | 54 | 12-18 years | Diabetes Self-Care Schedule | Effective regimen predicted better dietary self-care.<br>Females had worse self care and metabolic control than did males. |
| Springer, Dzura, Tamborlane, Steffen, Ahern, Vincent, Weinzimer. (2006) | Optimal control of type 1 diabetes mellitus in youth receiving flexible treatment | Retrospective Descriptive Correlation | Gender | 455 | < 18 years<br>11.8 (mean) years | HbA1c for glycemic control (no self-management measures) | Females had worse metabolic control |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Streisand, Respess, Overstreet Gonzalez de Pijem, Chen & Holmes (2002) | Brief Report: Self-care behaviors in children with type 1 diabetes living in Puerto Rico | Descriptive Correlation | Gender | 41 | 12.6 years (mean) | 24 hour recall interview measures not well described | Younger age, female gender was associated with better self care behaviors |
| Williams (1999) | Gender, adolescence and the management of diabetes | Qualitative Descriptive | Gender | 20 | 15-18 years | Flexible Semi-structured Guided conversations | Gender had a major impact on self care. Females had poorer adherence |

One explanation for some of the conflicting data between male and female self-management behavior may be the way data were analyzed to aggregate female and male cohorts. When data were analyzed by aggregating chronological ages together, there may have been no consideration for the developmental differences inherent between genders at different time points. Most reviewed studies placed all age groups within their gendered analysis. Males may begin puberty and meet developmental milestones as much as two years later than females (Brink, 1997; Dashiff, 2001; Petersen & Leffert, 1995) and the developmental differences may account for the discrepancies presented in the literature. Additionally, investigators used many different outcomes measures of self-management making it difficult to synthesize results. The data are conflicting and the large multi-site sample and reliable measure of self-management available for this secondary analysis may help to clarify the relationship of gender to self-management by stage of adolescence.

### *Summary*

Self-management behaviors for adolescents during the early, middle and late stages of adolescence will be investigated to examine differences in Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals. A study that has analyzed data by stage of adolescence and all elements of self-management has not been done and may assist to understand the potential risk or protective factors posed by gender, DOI (trajectory) and treatment regimen (flexible or conventional). This study will investigate how specific variables can influence self-management behaviors throughout stages of adolescence. There are few studies in the literature that describe self-management behaviors by developmental stage and it is has been suggested that self-management changes over the course of adolescence (Schilling et al., 2006). By describing T1D self-management behaviors in the early, middle and late stage of adolescence, clinicians and researchers can begin to understand the risk and protective factors that influence self-management behaviors. Interventions that are implemented at opportune times can then be developed to mitigate risk factors and augment protective factors.

# Chapter II

## Conceptual Framework

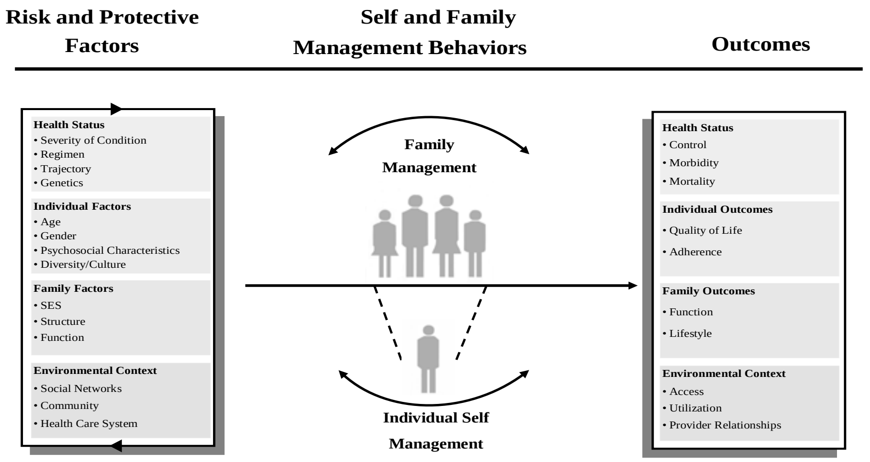
### Framework for the Study of Self-and Family Management of Chronic Conditions

The conceptual framework that guided this study is based on the work of Grey, Knafl, & McCorkle (2006) (See Figure 1). It was chosen for use in this study because of the inclusion of multiple variables that capture the complex nature of self and family management of a chronic illness, and because it was the guiding framework for the parent study from which this secondary analysis was taken (Schilling, Knafl, Grey, Lynn, Murphy, Dumser & Dixon, 2009). Further, the framework provided pragmatic utility for guiding inquiry because the different areas of the framework include variables that can be reliably measured and provide direction to guide research. Grey and colleagues (2006) have considered that *self*-management takes place in the context of families and recognize this to be so regardless of the age of the population under investigation. However, the family context is especially pertinent to adolescents as they transition from dependent to independent self-management. This provided an additional impetus to use this framework as it lends itself well to the adolescent population under investigation in this study.

The Self and Family Management Framework, was developed to …"specify key aspects of self and family management, therein providing direction for future research and further development and testing of a theory of self-and family management of illness" (Grey et al., 2006, p. 278). This framework was developed by an extensive literature search using the terms self care, self-management, family management and chronic conditions. After the search, an extensive literature review and analysis resulted in the identification of relevant themes that were then organized under broad conceptual areas. The broad conceptual areas form an umbrella of factors that are thought to pose a risk or protective influence to optimal self-and family management behaviors (Table 7) and potential outcomes of optimal self-management behaviors (Table 9).

Figure 1. The Self and Family Management Framework

**Figure 1. Self and Family Management Framework**



Grey, Knafl, and McCorkle, 2006

From “A framework for the study of self-and family management of chronic conditions”, by M. Grey, K.A. Knafl & R. McCorkle, 2006, *Nursing Outlook*, 54(5), p. 282.

*Risk and Protective Factors*

The framework suggests that there are specific variables under broad conceptual areas that pose risk or protective influence to optimal self management behaviors. Those broad conceptual areas and corresponding variables are: *health status* (condition severity, regimen, trajectory, and genetics), *individual factors* (age, gender, psychosocial characteristics, and culture), *family factors* (socio-economic status, structure, function) and *environmental* context (social networks, community, and health care system). Each of these variables can influence self-management behaviors and can be studied individually or with others.  The suggested relationship between self management and the variables are presented in Table 7.

Table 7. The Relationship of Risk and Protective Factors to Self-Management

| Condition Factors (Health Status) | Relationship |
|---|---|
| Severity | Higher severity, higher self-management needs |
| Regimen | Higher complexity, higher self-management needs |
| Trajectory | Variable, depending upon condition and stage |
| Genetics | Variable, depending on condition |
| Individual Factors | |
| Age | Variable, younger and older age, higher family management needs |
| Gender | Variable, women may neglect self-management |
| Diversity | Variable, but largely unknown |
| Psychosocial Characteristics | |
| Depression | Decreases self-management capability |
| Self-efficacy | Enhances self-management ability |
| Integration | Enhances self-management ability |
| Family Factors | |
| Socioeconomic status | Lower status associated with poorer self-management |
| Structure | Largely unknown |
| Function | Higher functioning, better self-management |
| Environment | |
| Social networks | More supportive networks, better self-management |
| Community | Variable |
| Health care system | Higher access, better self-management |

From “A framework for the study of self-and family management of chronic conditions”, by M. Grey,  K.A. Knafl & R. McCorkle, 2006, *Nursing Outlook*, *54*(5), p. 280

*Health Status/Condition Factors*

Health status factors are those that are condition-related and influence need for self- and family management.  The severity of the condition is seen by the provider as the prognosis, while it may be seen by the individual/family as perceived burden of the condition.  Regardless, the severity of the condition is likely to impact the degree of self-management, with more severe conditions requiring more self management.  Similarly, the regimen used to treat the condition is also important, with higher complexity meaning higher self-management needs.

Grey and colleagues (2006) used the analogy of thyroid medication being used to treat hypothyroidism as a relatively simple self-management regimen compared with something more complicated such as diabetes self-management regimens.

The next health status/condition factor in the model is trajectory. Trajectory refers to the various stages people go through over the course of a condition (Table 8) and includes the overall impact of the condition on the family and individual's social world. This factor was derived from a nursing model for chronic illness management based on the trajectory framework originally reported by Corbin and Strauss (1991) and later revised by Corbin in 1998. There are many variables that impact these stages over time such as: physical symptoms, impact on the social world and episodic exacerbation of the condition. The relationship of trajectory to self-management is variable depending upon the condition and the trajectory stage the individual is in. Lastly, genetics were reported to have a variable influence on self-management and associated outcomes depending on the condition. Table 8 shows the characteristics and interventions for stages of trajectory.

Table 8. Stages of Trajectory

| Stage | Characteristics | Interventions |
|---|---|---|
| First | Before onset of symptoms | None |
| Acute | Onset of symptoms | Active to support management |
| Stable | Maintain health | Various degrees of intervention |
| Unstable | Exacerbation of illness | Promote coping and stability |

Adapted from "A framework for the study of self-and family management of chronic conditions", by M. Grey, K.A. Knafl & R. McCorkle, 2006, *Nursing Outlook*, *54*(5), p.280.

### *Individual Factors*

Individual factors include age, gender, psychosocial and diversity/culture variables, and their influence on self-management is variable. Age is especially important given that very young and very old are more likely to be dependent upon family for self-management than on self. Even as children age and enter into young and middle adulthood, families continue to have an influence on self-management. For example, the responsibility of caring for a family, attending to a career and even aging parents may influence how an individual cares for their own condition. Inherent gender differences may have a variable influence on self-management behaviors and, according to Grey and colleagues (2006), females are more likely to neglect their own self-management than males.

The individual factor of diversity/culture is depicted in the framework and this may be measured as ethnicity/race. While it is understood that ethnicity and race are conceptually not the same as diversity/culture it is pragmatic to use an individual’s race as a proxy measure of culture in lieu of a valid and reliable measure of culture. As such, it has been known for some time that certain culture groups experience higher rates of some diseases (e.g. diabetes) (CDC, 2008). Further, when experiencing illness, certain groups will have worse *outcomes* (higher morbidity and mortality) when affected by a disease condition (e.g. heart disease) than other groups (CDC, 2008). However, the relationship between diversity and self-management *behaviors* remain largely unknown. This is not surprising given perceptions of health and illness are influenced by culture, which is naturally diverse and as noted, difficult to measure. So the self-management practices related to maintaining health and dealing with illness will differ between diverse groups and will likely vary (contingent upon the disease) within those groups. In other words, living with a chronic illness may elicit different self-management behaviors from different groups.

Self-management takes place in the context of the family and the overall impact of family relationship, structure and function are important contextual influences of self-management. In the framework, family factors include the variables of SES, structure and function. According to Grey and colleagues (2006), their review of the literature showed that higher family functioning, (specifically the variables of closeness, coping skills, support and communication) has a positive impact on self-management and educe better outcomes. As expected, they reported that lower SES is associated with poorer self-management. Lastly, they report the relationship to family structure (e.g. single, extended family) to self-management to be unknown.

The environmental factors are displayed last in the model, and include the variables of social networks, community and health care system. It is well documented that more supportive social networks result in better self-management (Sawyer & Aroni, 2005). Community is reported to have an unknown influence on self-management in the framework. Health care system variables refer to access to health care. The suggested relationship is that better access may also equal better self-management.

### *Self and Family Management Behaviors*

Schilling and colleagues (2006) include consideration for the interactions of risk/protective factors, self and family management behaviors and outcomes of self-management. As illustrated by the curved bi-directional feedback arrows surrounding the family and individual under the umbrella of the self-management behaviors, there is a transactional nature of self-management. What this means is that self-management is complex and is influenced on some level by all of the variables in the framework which, subsequently, has a direct influence on outcomes. Self-management is in the midst of this arrow; at the bottom of the middle of the model are options for nursing interventions to augment self-management behaviors. However, self and family management behavior is an area that has not been well studied, so the relationship between risk and protective factors and self-management behaviors remain largely unknown. According to the framework, what we know about the relationship of some of the risk and protective factors to self-management the context has been focused on self-management *needs* and not necessarily *behavior*s. Grey and colleagues (2006) note that of those studies that did examine the relationship of individual risk and protective factors to self-management behaviors, most did not include multiple factors. Many studies have reviewed the relationship of risk or protective factors and correlated them with an outcome variable (e.g. metabolic control, quality of life [QOL]), skipping the behaviors in the middle of the model that may have a direct impact on the outcome. Hence, the relationship of risk and protective factors, to self and family management behaviors remain largely unknown

### *Outcomes*

As outlined in Table 9, the suggested relationship between optimal self-and family management outcomes are similar: optimal self-management behaviors in the middle of the model result in improvement in the outcome on the right of the model. The outcome variables of self-management are numerous and include all aspects of self-managing a chronic condition, rather than focusing solely on physiological outcomes such as disease control and prevention of complications. The four broad outcome areas and their specific variables are: improved *health status* (control morbidity, mortality), *individual* (QOL, adherence), *family* outcomes (function, lifestyle) and *environmental* outcomes (access,

Table 9.  Potential Outcomes of Optimal Self-and Family Management

| | |
|---|---|
| Health status | |
| Control | Improved self-management, improved disease control |
| Morbidity | Improved self-management, improved morbidity |
| Mortality | Improved self-management, improved mortality |
| Individual | |
| Quality of life | Improved self-management, improved quality of life |
| Adherence | Improved self-management, improved adherence |
| Family | |
| Function | Improved self-management, improved functioning |
| Lifestyle | Improved self-management, improved lifestyle behaviors |
| Environment | |
| Access | Improved self-management, improved access |
| Utilization | Improved self-management, improved utilization |
| Provider relation | Improved self-management, improved |

From “A framework for the study of self-and family management of chronic conditions”, by M. Grey,  K.A. Knafl & R. McCorkle, 2006, *Nursing Outlook*, 54(5), 283.

There are close ties to the first two broad outcome areas in the model: health status and individual outcomes, and, as such, they are presented together here.  Under the broad umbrella of health status outcome variables are the variables of control, morbidity and mortality.  Some of the outcome goals of self-management are to enhance health status outcomes by improving or controlling the illness (control), preventing complications or the worsening of complications (morbidity) or death (mortality). Individual outcomes are related to QOL and adherence.  The authors of the framework note that QOL is an important factor in the reduction of morbidity and mortality outcomes, as is adherence.  The recognition that assisting patients to function and feel better can result in improved QOL is noteworthy. Patients should strive for optimal performance of their prescribed regimen (adherence),which would be aimed at enhancing the patient’s physical, social and psychological well being (QOL). However, there is some overlap between self-management behaviors and adherence. Self-management is multifactoral, and includes the many things an individual does to care for their condition.  Assuming an individual does as their health care provider suggests to a reasonable degree it also includes adherence. Therefore, if you have good self-management, it will include reasonable adherence to health care provider recommendations.

The family outcomes variables are function and lifestyle. The framework was developed with the caveat that "...family intervention research is in its infancy..." (Grey et al., 2006, p. 283). The framework includes recognition that there are some studies that suggest enhancing management of conditions does improve family functioning in addition to patient outcomes. As such, the lifestyle of the individual and family would also improve.

Lastly, as with most of the outcome variables, the relationship of environment to self-management is positive in all areas. By improving self-management, there will also be an improvement in the environmental variables: access, utilization and health care as well as positive provider relations. The authors report that the environmental context of managing a chronic illness has been the topic of several studies. This is important in understanding which access, utilization and provider factors may be implicated in putting specific populations at risk for poorer health outcomes.

## Dissertation Study

### *Risk and Protective Factors*

The variables chosen for this secondary analysis were determined by the nature of the data collected in the parent study. From the available risk and protective variables, four were selected. They were: two health status factors: regimen and trajectory and two individual factors: age and gender. These variables were chosen secondary to an extensive literature review that revealed relatively little definitive evidence regarding how potential risk and protective factors influence self-management behaviors in adolescents with T1D. These data were collected with a demographic form, and, as such, represents a reliable measure of the variables under investigation in the dissertation study. These risk and protective factors will be investigated for their relationships to self-management: Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals. The suggested relationship of these variables is presented in Table 10.

Table 10. Risk and Protective Factors Under Investigation for this Study

| Factor | Proposed Relationship |
|---|---|
| Condition Factor | |
| Regimen | Higher complexity, higher self-management needs |
| Trajectory | Variable, depending on condition and stage |
| Individual Factors | |
| Age | Variable, younger and older age, higher family management needs |
| Gender | Variable, females may neglect self-management |

From “A framework for the study of self-and family management of chronic conditions”, by M. Grey, K.A. Knafl & R. McCorkle, 2006, N*ursing Outlook*, *54*(5), p.280.

The data from risk and protective factors gathered in the parent study that were not used in this analysis include: psychosocial (self-efficacy), diversity (race/ethnicity) and SES (median income) and health care system (insurance status). The first variable, self-efficacy, was not used because it was determined that this was an area that is conceptually complex and required an extensive literature review and would be best served as an individual variable in its own study. The second, diversity, was not used because, although representative of the general population with T1D, the parent study sample did not have enough diversity dispersion to draw conclusions about any race or ethnicity other than white (80%) hence limiting external validity. The SES variable was not included because it was determined that the median income gathered by the United States census data in the parent study was not a valid and reliable proxy measure for SES. Lastly, because all participants were recruited from their primary diabetes care provider the health access variable of insurance status would not likely contribute meaningful information as a potential risk or protective factor for optimal self-management behaviors because most were insured.

### *Health Status Variables*

Health status factors are those that influence the severity of the condition, the complexity of the regimen required to manage it and the trajectory individuals and families experience as a result of the condition. Health status factors will have significant impact on self-management needs and therefore directly impact self-management behaviors. The health status variables under investigation in this study were the regimen (flexible or conventional ) and trajectory (measured by duration of illness).

### *Regimen*

The interaction between regimen and self-and family management is recognized to significantly impact an individual and family lifestyle and, hence, their social world. The more complicated a treatment regimen, the more self-and family management is required to manage the regimen. There are two different types of regimens that can be used to manage T1D in adolescents; conventional and flexible (ADA, 2005).

Adolescents using a conventional management regimen often require administration of a combination of rapid-, short-, intermediate- and long-acting insulin, before meals and in the morning and before bed to maintain optimal blood glucose control (ADA, 2005). Adolescents may have a large snack between meals, so an extra injection of rapid-acting insulin may be necessary, totaling two or three injections of insulin per day and BGM, at least four times per day is recommended (ADA, 2005). Meals and snacks are consumed on a fairly consistent time schedule and include a predetermined count of carbohydrate grams. The overall goal of a conventional treatment regimen is to avoid acute complications such as, severe hypoglycemia and hyperglycemia (Silverstein et al., 2005).

Flexible (commonly referred to as intensive) regimens involve a basal/bolus insulin administration of a rapid-acting and long-acting insulin combination in as many as six or seven MDI or through a CSII. Because the dose for the rapid acting insulin is based on blood glucose level, carbohydrate consumption and physical activity, more frequent BGM and insulin adjustments are needed, taking all these factors into account (Silverstein et al., 2005). The goal of flexible therapy is the normalization of glucose metabolism (Silverstein et al., 2005). While flexible regimens offer the option for better glycemic control and greater flexibility with activity and food intake (DCCT, 1993) they are more complex than conventional regimens and require more complex self-management.

### *Trajectory*

Given that the trajectory of a condition changes over time (Table 8), its impact on self-management is variable (Table 10) depending on the chronic condition and stage an individual is in. There is no set chronological time frame for individuals to move from one stage to another and this is influenced heavily by exacerbations/complications of the illness (e.g. DKA). This makes developing a valid and reliable measure of trajectory very difficult. Therefore, it is reasonable to measure trajectory by a proxy measure, such as duration of illness (DOI), or length of time in years or months since diagnosis. In fact, a common way to maximize generalizability in studies is to study subjects that are at a similar stage in their trajectory (e.g. stable at 18 months since diagnosis). This is accomplished by placing a minimum time line on the inclusion criteria for study participation. This is increasingly important for intervention research as noted by McCorkle and colleagues (1998). In their study of spouses of cancer patients, they found that interventions should be specific to the stage of illness an individual is in. Similarly, Grey and colleagues (1998) initiated coping skills training (CST) in adolescents with T1D who had initiated flexible regimens with an insulin pump, but excluded those who had not been using the therapy for more than six months to give individuals a chance to move toward a stable phase after an unstable phase following initiation of this regimen. Conversely, researchers and clinicians who want to provide interventions to assist individuals and families to cope with the diagnosis at the acute phase of diabetes would want to have newly diagnosed (less than six months) patients as part of their inclusion criteria.

### *Individual Factors*

Individual factors are also personal characteristics or demographic variables and, as such, are not subject to manipulation. Although the individual risk and protective factors can not be changed, it may be possible to change the self-management behaviors that are influenced by them. In order to better inform interventions that may improve self-management behaviors, this study will provide data on how the individual variable of age (stage of adolescence) and gender may influence self-management behaviors. Because of developmental differences inherent in males and females, understanding differences in a range of ages is useful as males reach puberty later than females (Petersen & Leffert, 1995). Gendered meanings of a chronic illness and differences in self-management behaviors are also important to assist in targeting areas of deficit to enhance behaviors that may be weak in either gender. This understanding will assist researchers and clinicians to target interventions that will improve outcomes at a particular stage of adolescence and/or with a specific gender group.

### *Age*

Age is a significant factor that influences how individuals and families self-manage a chronic disease with very young and very old age being implicated in higher family management needs (Grey et al., 2006). As children become older and spend more time away from home, they are more independent and take on more responsibility for self-management (Schilling et al., 2006). Adolescents are a particularly vulnerable population because there is a decline in family management as responsibility shifts to self as youth move from adolescence and into adulthood (Schilling et al., 2006). This transitional period has been associated with a decline in many of the outcomes commonly associated with self-management (e.g. Hba1c) (Wiebe et al., 2005). In order to account for the developmental differences present in any chronological age, for this study, the continuous variable of age present in the framework and parent study, will be transformed into an ordinal level of measurement as stage; early, middle, and late adolescence.

### *Gender*

Youth become increasingly aware of their gendered identity beginning in early adolescence. Gender has been linked to differences in the way males and females integrate chronic illness into their identities (Petersen & Leffert, 1995). Helgeson and Novak (2007) reported that females perceive illness as central to the self and, because of this, there are stronger implications for behaviors related to their illness. This may be why females engage in far greater diabetes *mis*-management than do their male counterparts (Brink, 1997). Further, it is during early adolescence that a sense of individual self is developing (Harter, 2003). If one’s self is differentiated based on a chronic condition this may have major implications on behaviors associated with that condition. Some data exist to support that female adolescents with T1D tend to have less problems with dependence, receive less encouragement from mothers and miss school more frequently than boys (Schmidt, 2007). Females also receive less support from their mothers, with the expectation they be more independent in their self-management (Williams, 1999, Schmidt, 2007).

According to the framework, females may neglect self-management in favor of caring for others. However, in the adolescent population, this may not be true as females at this age may not be caregivers. Understanding the influence of age as a potential risk or protective factor will help clinicians be aware of gendered nuances so that young men and women with T1D can be appropriately supported.

### *Self Management Behaviors*

The self-management behavior variables used in this study were those derived from an extensive instrument development study which served as the parent study for this analysis. Self-management behaviors vary depending upon the age of the patient and the condition, so specific variables for self-management are not present in the framework. For instance, self-management for adolescents with T1D as measured by the SMOD-A include: Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals (Schilling et al., 2009). This dissertation study is the first to explore the relationship of risk and protective factors to self-management of TID in adolescents using a self-management instrument that includes a conceptually diverse and comprehensive set of items.

### *Outcomes*

Although the parent study included two outcome variables, QOL and control (HbA1c), these variables will not be included in the dissertation study. I will examine differences in self-management behaviors between age groups and according to regimen, DOI and gender. This study has utility for clinicians and researchers for its contribution to descriptive knowledge about the specific variables that may pose risk and protective factors to optimal self-management. This can provide a foundation for interventions that can be developed and targeted toward enhancing self-and family-management, mitigating risk factors and/or enhancing protective factors to improve behaviors and hence outcomes.

## Use in Prior Studies

Because this framework is relatively new (2006), it has not been the subject of empirical testing, but it has been used to guide inquiry in empirical study, including the parent study of this analysis (Schilling et al., 2009). Other than the parent study, the Self-and Family Management Framework was used to guide one other study (Chyun et al., 2006). A cross-sectional descriptive survey design was used to describe attainment of glucose and coronary heart disease (CHD) risk factor goals as well as to identify risk and protective factors associated with successful goal achievement in adults (aged 50 to 75 years) with Type 2 Diabetes (T2D). The specific variables under investigation in this study were: *individual factors* (age, gender, level of education, personal model beliefs about health (exercise, BGM, checking feet), *illness-related* (medications used to control diabetes, along with antihypertensive and lipid-lowering therapy and duration of diabetes, < 3 hours/week of physical activity), and *family-related factors* (marital status and with whom the subject was living, employment, and income). The outcome variables were: *illness outcomes* (body mass index [BMI], waist circumference, HbA1c, blood pressure [BP], low-density lipoproteins [LDL], and high-density lipoproteins [HDL], triglycerides [TG]).

Study findings from Chyun and colleagues support that illness-related factors of a longer duration of diabetes (>2.5 years) was associated with not achieving glucose and BP control, insulin use without meeting glucose control and waist circumference goals, and anti-hypertension therapy with not meeting BP, BMI and TG. Of note, family-related factors of higher income (>$50,000) were associated with higher HbA1c and BMI, living alone with higher LDL, and support without making HDL and TG Goals. Measures of family-related factors were less consistently associated with illness outcome measures.

Results from this study suggested that the outcomes in the model varied depending upon the individual, illness and family factors under investigation. In other words there were a variety of factors associated with illness outcome variables and no one single factor was a predictor of poor self-management outcomes. The individual, illness and family-related factors do have a role in goal attainment. However, this study makes assumptions that participants practiced optimal self and family management behaviors, which further highlight the need to investigate how health status, individual and family factors influence self-and family-management *behaviors* and then how those factors influence *outcome* variables.

### *Summary*

The Self-and Family Management Framework provides a theoretical framework that is useful to increase understanding of the risk and protective factors associated with self-management behaviors and associated outcomes. The negotiation between self-and family-management during adolescence is important. As teens negotiate independence, it is imperative to consider the factors that influence their self-management behaviors and, subsequently, outcomes. Although many of the risk and protective factors in the model have been studied in terms of outcomes, many reports have not described these factors as they relate to self-and family-management behaviors, the middle of the model. While it is recognized that further work is needed to develop and test this framework, it provides a sound foundation to guide this study.

# Chapter III

## Methods

### *Introduction*

This chapter will describe the methods for this study which was a secondary data analysis of data collected in an instrument development study. The purpose of this secondary analysis was to describe T1D self-management behaviors in early, middle and late stages of adolescence. To date, few studies have examined differences in self-management behaviors in stages of adolescence; most report the mean or range of ages of participants in a study. Similarly, no studies have examined all of the attributes of self-management behaviors as delineated by Schilling et al. (2002) including activities of self-management, processes of self-management (including collaboration with parents and health care providers) and self-management goals (Schilling et al., 2002). This study will also examine whether the roles of covariates (regimen, DOI, gender) in self-management behaviors vary by stage of adolescence. This is the first study to examine the potential risk and protective factors of regimen, duration of illness and gender on TID self-management behaviors by stage of adolescence.

In order to accomplish the purpose of this study, a secondary data analysis was conducted using data collected from the MOST study (parent study), from which the Self-Management of Diabetes in Adolescence (SMOD-A) was developed. The large multi-site data set from the MOST study made it possible to examine potential risk or protective factors and their influence on self-management behaviors across three specific adolescent age groups.

## Description of the Parent Study

### *Purpose*

The original instrument development study resulted in the creation of the SMOD-A (Schilling et al., 2009). This instrument can be used to measure self-management in adolescents with T1D, and gives researchers and clinicians the options of a self-report measure. Until the SMOD-A, most available instruments evaluated performance of diabetes care activities, but lacked an approach to comprehensive measurement of self-management (Schilling, Grey & Knafl, 2002). The Diabetes Self-Management Profile (DSMP) (Harris et al., 2000) has been used in some recent research reports, but not only does it not measure process and goals, but it also is an interview measure and, as such, is more time-consuming to administer and score than the SMOD-A.

### *Design and Methods*

The MOST study, (RO1NR08579), funded by the National Institute for Nursing Research (NINR), was conducted from 2005-2008. The purpose of the MOST study, from which the data for this analysis will be accessed, was to develop the SMOD-A and assess its psychometrics properties. The instrument development was done in a three-phased process. The first phase was a qualitative descriptive study in which 22 youth, ranging in age from 8 to 19 years, and one of each of their parents, were interviewed about the management of diabetes. Interview transcripts were subsequently used to write items for the SMOD-A (Schilling et al., 2007). From this qualitative study, 99 items were written in the three categories identified as the critical attributes of self-management of T1D: activities, process, and goals (Schilling et al., 2002).

The second phase of instrument development was to determine the content validity of the instrument (Schilling, Dixon, Knafl, Grey, Ives & Lynn, 2007). This study was unique in that it used experiential experts (adolescents and parents, *n*=11) and professionals (diabetes clinicians and researchers, *n*=17) to evaluate the content validity of the SMOD-A. The content validity was evaluated for the 99 items derived in the qualitative study (phase one). The content validity index (CVI) was calculated for the experiential group (adolescents and parents) and the total group, which included the experiential group as well as clinicians and researchers. Of the initial 99 items, 6 had CVIs (calculated for the entire group) that did not meet the predetermined cutoff of .80 and were eliminated. From those remaining, there were 20 items where the CVI was > .80 for the total group but the CVI for the experiential group, alone, was < .80. Each of these items were evaluated critically and there were 3 that were kept as written, 7 were eliminated, and 10 were revised as suggested by the experiential experts. The CVI for the remaining 86 items was .927. The third and final phase was to field test the SMOD-A and to determine its psychometric properties..

### *Sample*

The sample for the field testing of the SMOD-A was composed of 515 adolescents from two major medical centers in the Northeast. There were 595 adolescents (age 13-21 years old) who were invited to participate. Of those, 60 declined and 20 did not meet enrollment criteria or did not complete the questionnaire packet. Inclusion criteria for the MOST study were: (1) between the ages of 13 and 21 years, (2) English speaking, (3) diagnosed with T1D for at least one year, (4) not pregnant, and (5) having no condition/chronic illness that could impact how the individual cared for their diabetes (e.g. mental disability or illness). A final sample of 515 adolescents participated in data collection. The age range was 13 to 21 years (mean = 15.8 years ± 2.14 years) and the gender mix of the sample was approximately equal (53% males). The sample was predominantly white (80% White, 9.7 % Black, 1.6% Asian, 8.8 % American Indian or Alaskan Native, Other or Multiple) with about 6 percent (5.8%) reporting Hispanic ethnicity. Over half (*n*=342, 66.4%) of the participants used flexible regiments to manage their diabetes and, of the total sample, almost half used CSII (*n* = 250, 48.5%) and (*n*=92, 17.9%) used MDI. The remaining portion of the sample (*n*=173, 33.6%) were on conventional regimens. The mean duration of diabetes was 6.92 years ± 3.92 years. The mean HbA1c, taken from the chart at the time of the clinic visit, was 8.47% ± 1.78%.

*Procedures*

Participants in the parent study were recruited through either a letter sent by their diabetes care provider or by a newsletter. Research assistants approached eligible adolescents in diabetes clinic waiting rooms. Eligible adolescents were given an explanation of the study, and invited to participate. If they agreed to participate, informed consent was obtained by adolescents older than 18 years, and parental consent and written adolescent assent was obtained from adolescent participants under age 18 years.

All the adolescent participants were given a booklet with the SMOD-A, four additional measures, and a demographic form (in this order) to complete independently in the waiting room of their diabetes clinic or at home**.** Additional measures included a diabetes-related adherence instrument, the Self-Care Inventory (SCI) ($\alpha$= 0.87) (LaGreca, Swales, Klemp and Madigan, 1988; LaGreca, 1992); a diabetes-related quality of life instrument, the Diabetes Quality of Life-Youth (DQOL-Y) ($\alpha$=0.76) (Ingersoll & Marrero, 1991); a measure of self-efficacy, the Diabetes-Related Self-Efficacy Subscale (SEDS) ($\alpha$= 0.92) (Grossman, Brink, & Hauser, 1991) and the CABS. Additionally, a small number (*n*=16) of participants at one site also completed the Diabetes Self-Management Profile (DSMP) ($\alpha$= 0.76) ( Harris et al., 2000) by telephone at a later time and date.

In order to assess stability, including test-retest reliability of the SMOD-A, some participants (*n*= 187) took the SMOD-A twice, at two weeks (*n*=74) or three months (*n*=113). Data were also collected on the most recent measure of metabolic control (HbA1c) and put on the demographic form included with the survey. Adolescents were paid $15.00 for their participation in the study, $30.00 if they completed the SMOD-A a the second time or were interviewed to complete the DSMP.

*Results*

The readability of the SMOD-A was evaluated using the Flesch-Kincaid Grade Level calculated in Microsoft Word. The Flesch–Kincaid Grade level readability test uses word and sentence length to indicate comprehension difficulty when reading English text. The Flesch-Kincaid grade level of the SMOD-A was 5.9. This means that adolescents who have completed their ninth month of fifth grade in the United States should be able to read and understand the SMOD-A content (Microsoft Corporation, 2008).

The SMOD-A was separated into two parts, I and II. Because of the different response options for Part I (61 items) than in Part II (12 items), two separate factor analyses were conducted. Missing data by item ranged from 0 to 16 (3.1% , *n*=83) for items, and the subjects with missing data were not included in factor analysis, leaving 432 for analyses.

Exploratory alpha factor analyses revealed five subscales -- Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals. Varimax rotation was used for factor rotation of the four factor solution (Part I) for the first four subscales (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, and Diabetes Communication). There was a single factor solution (Part II) for the last subscale (Goals). Items with factor loadings of .20 or greater were included in analyses of subscale reliability, but items detracting from reliability were dropped. This resulted in the final version of the SMOD-A, a 52-item instrument with the following internal consistency reliabilities for the five subscales: Collaboration with Parents ($\alpha$=0.85), Diabetes Care Activities ($\alpha$=0.77), Diabetes Problem Solving ($\alpha$=0.71), and Diabetes Communication

($\alpha=0.73$) and the one factor solution was Goals ($\alpha=0.75$). Stability correlations were acceptable ranging from 0.60 - 0.88 at two weeks ($n= 74$) and 0.59-0.85 for three months ($n=113$).

The other measures in the MOST study (DQOL, SEDS, SCI,CABS) were selected to assess the construct validity of the SMOD-A. Hypothesized relationships between the SMOD-A and these measures were tested to assess the construct validity of the SMOD-A, and results supported the construct validity of the SMOD-A.

The Collaboration With Parents subscale had significant positive correlations with the SEDS ($r=.23$, $p=.0001$) and the SCI ($r=.29$, $p=.0001$). The Diabetes Care Activities scale had significant negative correlations with the DQOL-Impact ($r=-.28$, $p=.0001$), DQOL-Worry ($r=-.24$, $p=.0001$) and the SEDS ($r=-.30$, $p=.0001$). There were positive correlations with the SCI ($r=.62$, $p=.0001$), DQOL-Satisfaction scale ($r=25$, $p=.0001$), DSMP-Insulin ($r=.53$, $p= \leq .05$), Diet ($r=.80$, $p= .001$), Glucose Testing ($r=.56$, $p<.05$) and Total ($r=.74$, $p=.00(1)$. The Problem Solving scale was found to be significantly negatively correlated with the DQOL-Impact ($r=-.14$, $p= .001$) Worry ($r= -.13$, $p= .\leq.01$), the SEDS ($r=-.38$, $p =.0001$). There were positive correlations between the Problem Solving Scale and the DQOL-Satisfaction ($r=.17$, $p=.001$) and the SCI ($r=.21$, $p=.0001$). There were negative correlations with the Diabetes Communication scale and the DQOL-Impact ($r=- .18$, $p\leq .01$) and the SEDS ($r=-.35$, $p=.0001$) and positive correlations with the DQOL-Satisfaction ( $r= .19$, $p=.0001$), SCI ($r=.34$, $p=.0001$) and DSMP-Exercise ($r=.52$, $p<.05$). Lastly, the Goals subscale was negatively correlated with DQOL-Impact ($r=-.23$, $p= .0001$), DQOL-Worry ($r=-.17$, $p= .001$) and the SEDS ($r= -.35$, $p=.0001$). There were positive correlations between the Goals scale and the DQOL-Satisfaction ($r=.15$, $p = .001$) and the SCI ($r=.24$, $p=.0001$).

The negative correlations between the SEDS , DQOL-Impact and DQOL-Worry and the SMOD-A subscales indicates that there is a significant negative relationship between SMOD-A subscale scores and SEDS subscale scores meaning self-management is negatively related to self-efficacy in that lower scores on the SEDS (meaning higher diabetes self-efficacy) were correlated with better self-management. The positive correlations with the DQOL subscale quality of life (impact and worries), indicates better self-management is associated with less impact and worries for adolescents. The positive correlations with the DQOL-Satisfaction, the SCI and the SMOD-A support that many elements of self-management are positively related to satisfaction with quality of life. and adherence (as measured by the SCI).

Interestingly, all of the SMOD-A subscales revealed significant relationships with HbA1c. Positive correlations were found only with one subscale: Collaboration with Parents ($r$=.11, $p$= $\leq$.01) meaning that an increase in the degree to which parents were involved in diabetes management is associated with a higher HbA1c. Negative correlations were found for the other four subscales which were correlated with a lower HbA1c (better metabolic control). Specifically they were: Diabetes Care Activities ($r$= -.24, $p$= .0001) indicating more frequent performance of key activities of diabetes management are associated with lower HbA1c, Diabetes Problem Solving ($r$= -.26, $p$ = .0001) meaning those adolescents who frequently adjust their regimen and know HbA1c numbers and Goals, are more likely to have lower HbA1c. Also, Diabetes Communication ($r$= - .10, $p$ = $\leq$ .05) meaning more adolescent communication with parents, health care providers and friends about their diabetes is associated with lower HbA1cs. Lastly, there were significant correlations with Goals ($r$= -.26, $p$ = .0001), meaning that an increase in the degree to which the adolescent endorsed seven potential diabetes goals was associated with better metabolic control.

## Dissertation Study

### *Purpose of the Secondary Analysis*

The purpose of this secondary analysis was to describe T1D self-management behaviors in early, middle and late stages of adolescence. In order to accomplish this, I examined differences in self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals) in early, middle and late adolescence (Aim 1). I also examined whether the roles of covariates (regimen, DOI, gender) in self-management behaviors vary by stage of adolescence (Aim 2).

## Measures

### *Demographic Data Form*

For this study, data on gender, age (which was used to create a new variable, stage of adolescence as: early 13-14 years, middle 15-16 years, and late 17-21 years), regimen (flexible or conventional) and duration of illness were utilized. The specific questions used to collect demographic data in the parent study are in Table 11.

Table 11. Demographic Data Utilized in the Secondary Analysis

| |
|---|
| Age |
| Length of time you have had diabetes |
| Gender<br>Male<br>Female |
| Ethnic<br>Do you consider yourself:<br>Hispanic or Latino<br>Not Hispanic or Latino |
| Racial Categories (Check all that apply)<br>American Indian or Alaskan native<br>Asian<br>Black or African American<br>Native Hawaiian or other Pacific Islander<br>White<br>Other |
| Are you currently on an insulin pump?<br>Yes No |
| If you take insulin injections (shots), do you usually take the same amount of insulin at the same time each day?<br>Yes No |

From the MOST study questionnaire.

*Self-Management of Type 1 Diabetes-Adolescence (SMOD-A).*

The SMOD-A (Schilling et al. 2009) consists of a 52-item self-report measure with five subscales identified through factor analysis. Part I measures how frequently adolescents perform activities related to caring for their diabetes and how frequently they confer or are influenced by others. The response options ranged from: “Never”, “Sometimes”, “Most of the time” and “Always”. Part II listed potential self-management Goals and asked adolescents to rate each of them with the following options: “No longer a goal for me”, “Never a goal for me”, “Sometimes a goal for me”, and “Definitely a goal for me”. The subscales of the SMODA were: 1) Collaboration with Parents, 2) Diabetes Care Activities, 3) Diabetes Problem Solving, 4) Diabetes Communication, and 5) Goals. The instrument had good content validity (CVI=0.93) and good subscale reliability levels were ($\alpha$ = 0.71 to 0.85). Content validity was determined by three panels of expert judges consisting of 12 clinicians from two university pediatric diabetes clinics, 5 behavioral diabetes researchers, and a group of 11 adolescents and parents as experiential experts.

The reliability and descriptive statistics were recalculated for the total secondary data analysis sample as well as for each stage of adolescence. The Cronbach alpha scores ranged from 0.69 (Problem Solving) scale to 0.84 (Collaboration with Parents scale) on the total sample. Reliability statistics for each subscale for each stage of adolescence and the total sample are reported in detail in the results section.

*Sample*

The original study reported data for 515 adolescents, age 13-21 years. The inclusion criteria for the secondary analysis were the same as for the parent study: (1) between the ages of 13 and 21, (2) English speaking, (3) diagnosed with T1D for at least one year, (4) not pregnant, and (5) having no condition/chronic illness that could impact how the individual cared for their diabetes (e.g. mental disability or illness). An additional exclusion criteria were those who do not live at home with parents (*n*=11) since there may be some inherent differences in self-management, specifically communication with parents. The demographic variables from the study sample are described below in Table 12.

Table 12. Demographic Variables and Sample from the Dissertation Study

| Demographic | Total Sample<br>*N*= 504 | Early<br>*n*=163 | Middle<br>*n*=159 | Late<br>*n*=182 |
|---|---|---|---|---|
| Variable | | | | |
| Ethnicity/Race | | | | |
| White | 423 (83%) | 136 | 129 | 159 |
| Black | 61 (12%) | 23 | 20 | 18 |
| Asian | 10 ( 2%) | 0 | 7 | 3 |
| Hispanic | 30 (5%) | 13 | 11 | 6 |
| American Indian/ Alaskan | 7 (1%) | 1 | 4 | 2 |
| Other | 16 (3%) | 4 | 8 | 4 |
| Gender | | | | |
| Male | 266 (52%) | 84 | 80 | 102 |
| Female | 238 (47%) | 79 | 79 | 80 |

The majority (64%, *n*=331) of the total sample from the secondary data analysis utilized flexible regimens to control their diabetes. The mean duration of illness was 6.92 (SD± 3.92) years since diagnosis and, as expected, increased across early (5.0, SD±3.44), middle (6.79, SD±3.73) and late (7.98, SD±4.20) stages. Table 13 describes the descriptive statistics for regimen and DOI for the dissertation sample.

Table 13. Regimen and Duration of Illness for the Dissertation Sample

| DOI | | | | Regimen | |
|---|---|---|---|---|---|
| | Mean | Median | SD | Flexible | Conventional |
| Early (*n*=163) | 6.92 | 6.0 | ± 3.92 | 111 (68%) | 53 (32%) |
| Middle (*n*=159) | 5.80 | 5.0 | ± 3.44 | 92 (58%) | 67 (42%) |
| Late (*n*=182) | 6.79 | 6.0 | ± 3.73 | 121 (66%) | 62 (34%) |
| Total (*N*=504) | 7.98 | 8.0 | ± 4.20 | 324 (62%) | 180 (37%) |

*Procedures*

Power analysis is a method for reducing the risk of a Type II error (wrongly accepting a false null hypothesis) (Polit & Hungler,1999). Therefore, a power analysis was conducted prior to analyzing the data for the secondary analysis in order to determine the ability to detect differences between groups for stages of adolescence (early, middle, and late) and self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals) and according to gender, duration of illness and treatment regimen (flexible or conventional).

A power analysis was conducted to determine the power necessary to determine the strength of the association to detect between group differences. The analysis was conducted using Statistics Calculator 2.00 program. This analysis used a power of 89% given the assumptions of an alpha of .05. With an ANOVA analysis, eta-squared is the index indicating the proportion of variance explained and can be used directly as an estimate of the effect size (Polit & Hungler, 1999). However, because there were no studies that have analyzed data by stage of adolescence the eta-squared could not be estimated based on prior research. Therefore, I used a power of 89% and determined an effect size and eta-squared to be 0.6 which is considered a medium effect size for the fixed sample size of 504.

I obtained approval (as an addendum to Dr. Schilling's MOST study IRB approval) from the institutional review boards (IRB) at the University of Massachusetts Worcester, Yale University and Children's Hospital of Philadelphia (CHOP). The data were already cleaned and prepared for this study and a new variable from age (stage of adolescence) was coded: early 13-14 years, middle 15-16 years, and late 17-21 years. The items that required reverse coding were already done before the SMOD-A subscale total was calculated in the parent study.

The de-identified data from the SMOD-A were received de-identified in SPSS version 15.0 by me for the secondary analysis study. In the original study, data were entered into two identical data bases. These databases had already been cleaned, eliminating discrepancies between them.

### *Data Analysis*

Once received, data were analyzed using SPSS 17.0. Analyses by specific aim were: Specific Aim 1: Examine differences in self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals) for early, middle and late adolescents.

The difference in self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals) by stage of adolescence (early, middle, and late) were determined by ANOVA.

ANOVA is a fairly robust statistical technique that was used to determine if group means for the three stages of adolescence (early, middle, and late) differ from one another.

To check model assumptions, I reviewed distribution for the outcome variables (self-management: Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals) for each of the three groups (early, middle, and late adolescents) to determine if each group is normally distributed. The variance was used to determine if the spread was similar across the three groups. The sums of squares between groups were viewed to determine the total, between-group and within group variation based on the deviations of the scores from means. In addition, box plots graphs for visual comparison also assisted with and adolescent stage-specific variances.

Stage-specific skewness was reviewed to check model assumptions of normally distributed residuals with the Kolmogorov-Smirnov (K-S) test. The *p*-value for this test may have been significant given the large sample size so even small departures from normality were detected (Munroe & Page, 1993). Therefore, I also reviewed a histogram for Cook's distance to determine influential observations. The variability of the groups were compared to determine the within-group, between group and total detectable differences. The R squared proportion of variability in self-management behaviors that were explained by the adolescent stage, were assessed as well.

The F–statistic (Ratio) was used to determine if the between-group difference were great enough to reject the null hypothesis (no differences in self-management behaviors among the three stages of adolescence). Because this did not reveal which groups differed, I used multiple comparisons to determine which stages differed in their self-management behaviors. Therefore, provided the null hypothesis is rejected (there are differences in the adolescent stages), I compared the stages with each other (multiple comparisons) in a post hoc for pair wise comparisons. A Bonferroni correction was applied to protect against a Type I error.

Specific Aim 2: Examine whether the roles of covariates (DOI, regimen, gender) in self-management behaviors vary by stage of adolescence.

Data for this aim were analyzed with a statistical method referred to as analysis of covariance (ANCOVA). ANCOVA combines ANOVA with regression to measure the differences among group means (Munro & Page, 1993). With ANCOVA, the dependent variable (self-management) was adjusted statistically to remove the effects of the portion of uncontrolled variation represented by the covariates (gender, regimen and duration of illness). This method was chosen because of the ability to reduce the error variance between stage of adolescence, gender, regimen and duration of illness with self-management behavior. Further, this method allowed for better predictability among covariates by allowing for continuous covariates (independent variables) (Polit & Hungler, 1999).

To check model assumptions, linear relationships between the co-variates (age, gender, and duration of illness) and dependent variable were determined by scatter plots. Each stage of adolescence group (early, middle, and late) were reviewed separately to see if the slopes for the co-variates illustrated a departure from linearity. Colinearity diagnostics were checked for the DOI and adolescent stage variables and no colinearity problems were detected.

The interactions were run for each of the between subject groups and those that were not statistically significant were omitted and the model re-run. The R squared ($r^2$) was reviewed to assess the residuals of the groups to see if they differed after the effect of the other variables was removed. I continued to re-run all variables to assess the differences before and after adjustment for the co-variates to see if there was an impact on the dependent variable. A post-hoc analysis was applied to determine which age groups were statistically significant after controlling for the co-variates. Between-subject effects for each of the dependent variables were reviewed to determine if there were significant interactions.

### *Missing Data*

Missing data in the parent study were 3.1% (n =83) and, by item, ranged from 0-16. Subjects with missing data on the SMOD-A were omitted from original factor analysis and reliability testing (Schilling et al., 2009). For total subscale scores, implied imputation (mean of items present multiplied by number of items in the subscale missing) was used (J. Dixon, personal communication, November 13, 2009). There were no observations with missing data on the demographic variables which served as covariates under investigation in this study (regimen, duration of illness, age and gender). For reliability analysis, missing data was omitted from analysis and, because the total subscale scores were used for the ANOVA/ANCOVA models, missing data were already imputed and used for analysis in this study.

### *Secondary Data Analysis: Methodological Issues*

Secondary data analysis occurs when data collected for another purpose are reanalyzed to address the current research question(s) or methods (Magee et al., 2006; Nicoll & Beyea, 1999). Similar to other research methods, there are advantages and disadvantages of secondary data analysis. Some of the major advantages of secondary data analysis are that data collection is less costly or non-existent and less labor and time intensive than primary data collection. Further, certain types of data are only available from secondary sources, and sample sizes are often large enough to power studies, allowing conclusions to be drawn by the researcher (Nicoll & Beyea, 1999).

A disadvantage of secondary data is a lack of a priori controls specific to the research conducted in the parent study. One of the first steps to minimize this issue in this study was to have a conceptual match between the primary data collection and existing data (Shepard, Carroll, Mahon, Moriarty, Feetham, Deatrick & Orsi, 1999). Conceptual congruence surrounding self-management can be problematic, given that it means different things to different people and is often described differently (e.g. self-care, adherence) in the literature (Lorig & Hollman, 2002; Schilling et al., 2002). In the parent study, attributes of self-management were determined by concept analysis (Schilling, Grey & Knafl, 2002), which was completed prior to the first part of the instrument development study. This gave reasonable assurance that the instrument measures what it purports to: self-management of T1D in adolescents. Additionally, because this secondary analysis was guided by the same framework as the parent study, conceptual issues were minimized and, as such, so were errors. Therefore, this adds to the validity and reliability of the secondary analysis because conceptual congruence is maximized since both studies were measuring the same construct, self-management.

Another potential limitation of secondary analysis is that all of the variables of interest may not be available if the researchers in the parent study did not collect that data. For example, in this study a variable of interest was socio-economic status (SES). The related data collected in the parent study were estimated income based on U.S. Census data and it was determined, for this study, that this was not a valid proxy measure for SES. Similarly, for this study it would have been preferable to have data on younger adolescents as well (11-12 years). All research has missing data and the amount must be evaluated carefully in a secondary analysis. Because of the large sample size, the relatively small amount of missing data in the parent study (3.1%) and the inability to determine if data were missing at random, it was determined that missing data in this study would be, and were, excluded from analysis.

### *Limitations*

Although Type 1 diabetes is rare in most Asian, African and American Indian populations and more common in Caucasians (National Institute of Diabetes and Digestive and Kidney Disorders [NIDDK], 2008), the lack of diversity in the sample (80% white) limited the generalizability of the findings to other ethnic groups. In addition, the sample was geographically limited to the Northeast United States. This limited the exploration of potential cultural differences among age stages for adolescents. An additional limitation included the alpha scale reliability ($\alpha = 0.69$) on the problem solving subscale and therefore analysis for this self-management behavior must be interpreted cautiously.

### *Ethical Considerations*

In the parent study, IRB approval was granted from both data collection sites and informed consent was obtained from participants > 18 and parental consent and adolescent assent was obtained from all study participants < 18. Ethical concerns regarding privacy were protected because data were transferred and maintained as de-identified so the researcher did not know the names of individual respondents. Further, study data bases were stored on a password secured computer and paper copies in a locked file cabinets in the study office's of both data-collection sites. Data from the dissertation study will be maintained for a period of only five years.

### *Summary*

The purpose of this secondary analysis was to describe TID self management behaviors in early, middle, and late adolescence. The Self and Family Management Framework was used as the conceptual framework for this study. It was anticipated that the study results would add to our knowledge about adolescent developmental level, self-management practice and the effects of gender, treatment regimen and duration of illness by stage of adolescence. A better understanding of adolescent age-related nuances of self-management behaviors could provide clinicians and researchers with more precise information to tailor care and interventions.

# Chapter IV

## Results

### Introduction

This Chapter presents the descriptive data for the sample included in the analysis as well as the results from the one way analysis of variance (ANOVA) and the analysis of covariance (ANCOVA). Reliabilities for the SMOD-A subscales are also included.

### Descriptive Data

*Sample*

Data from 504 subjects were analyzed after removing 11 from the original sample data that were not living with their parents. The majority of the participants for this study were Caucasian (81%), with a slightly higher male (52%) to female ratio. The duration of illness (DOI) ranged from 1-17 years with a mean of 6.90 years (SD ±3.90). The age range was from 13-21 years. The age variable was transformed into three adolescent stages early (13-14) (*n*=163), middle (15-16) ( *n*=159) and late (17-21) (*n*=182) with normal distribution across the total adolescent sample. The majority of participants (*n* = 324, 64%) used a flexible regimen and about half (*n*=245, 48%) used an insulin pump. The mean glycemic control (HbA1C) for the total sample was 8.43% and the median was 8.20% and the mode was 7.20%. Table 14 depicts the sample characteristics for the secondary analysis.

Table 14. Sample Characteristics (*N*=504)

| | Early<br>(13-14)<br>*n*=163 (32%) | Middle<br>(15-16)<br>*n*=159 (32%) | Late<br>(17-21)<br>*n*=182 (36%) | Total Sample<br>(13-21)<br>*N*=504 |
|---|---|---|---|---|
| Ethnicity/Race | | | | |
| White | 136 (83%) | 129 (81%) | 159 (87%) | 423 (81%) |
| Black | 23 (14%) | 20 (13%) | 18 (10%) | 61 (9%) |
| Asian | 0 | 7 ( 4%) | 3 ( 2%) | 10 (1%) |
| Hispanic | 13 ( 7%) | 11 (7%) | 6 (3%) | 30 (4%) |
| American Indian/<br>Alaskan | 1 (0.5%) | 4 (3%) | 2 (1%) | 7 (.2%) |
| Other | 4 (2%) | 8 (5%) | 4 (2%) | 16 (1%) |
| Gender | | | | |
| Male | 84 (51%) | 80 (50%) | 102 (56%) | 266 (52%) |
| Female | 79 (48%) | 79 (50%) | 80 (44%) | 238 (47%) |
| Regimen | | | | |
| Conventional | 52 (32%) | 67 (42%) | 61 (34%) | 180 (36%) |
| Flexible | 111 (68%) | 92 (58%) | 121(66%) | 324 (64%) |
| Insulin Pump | 85 (42%) | 71 (45%) | 89 (49%) | 245 (49%) |
| Duration of Illness | | | | |
| Mean | 5.82 | 6.74 | 8.01 | 6.90 |
| SD ± | 3.44 | 3.69 | 4.17 | 3.90 |
| Median | 5.0 | 6.0 | 8.0 | 6.0 |
| Range | 1.0-13.0 | 1.0-16.0 | 1.0-17.0 | 1.0 – 17.0 |
| HbA1C | | | | |
| Mean | 8.34 | 8.55 | 8.40 | 8.43 |
| SD± | 1.60 | 1.68 | 1.91 | 1.74 |
| Median | 8.30 | 8.40 | 8.20 | 8.20 |
| Range | 5.1-14.0 | 5.6-14.0 | 5.3-14.0 | 5.1-14.0 |

A chi-square analysis was run to compare the three age groups by ethnicity/race, gender and regimen. Only one significant $X^2$(2, *n* = 7) = 0.325, *p* = .002) difference was found for the Asian ethnicity in the middle and late adolescence adolescent stage groups.

An ANOVA was run to determine differences between adolescent stage groups and DOI. There were significant differences (*F*(2,503) = 14.380, *p*=.000) between the adolescent stage groups. Adolescents in the late stage had longer DOI compared to both early and middle stage adolescents. Table 15 displays the results from ANOVA including the bonferroni post hoc tests for stage of adolescence and DOI analysis.

Table 15. Analysis of Variance for DOI and Adolescent Stage

| | Sum of Squares | *df* | Mean | F | P-Value |
|---|---|---|---|---|---|
| Between Groups | 415.883 | 2 | 207.916 | 14.380 | .000** |
| Within Groups | 7243.596 | 501 | 14.458 | | |
| Total | 7659.429 | 503 | | | |

Bonferroni Post Hoc Tests

| Value | Age Category | | | Mean Difference | SE | P |
|---|---|---|---|---|---|---|
| | Early | Middle | Late | | | |
| Early | | X | | -.913 | .423 | .095 |
| | | | X | -2.182 | .410 | .000** |
| Middle | X | | | .913 | .423 | .095 |
| | | | X | -1.268 | .412 | .007** |
| Late | X | | | 2.182 | .410 | .000** |
| | | X | | 1.286 | .412 | .007** |

**p<.05

### *Internal Consistency*

Reliability was determined by calculating Cronbach's alpha scores for each of the subscales on the SMOD-A for each of the three groups of adolescents and for the total secondary analysis sample. Participants with missing responses were omitted from the reliability analysis and ranged from 6.2% (*n*=31) on the Diabetes Care Activities subscale (N=473) to 1.2% (*n*=6) cases on the Diabetes Problem Solving and Diabetes Communication subscales (N=498).

The results for the total adolescent sample included a range from minimally acceptable (α= 0.69) on the Diabetes Problem Solving subscale to good (α.= 0.84) on the Collaboration with Parents subscale. Analyses were also computed for each of the individual adolescent stage groups (early, middle, late). The scores for each individual stage ranged from undesirable (α= 0.62) for early adolescence on the Diabetes Care Activities subscale to very good (α= 0.84) for late adolescence on the Collaboration with Parents subscale. The most problematic was the Diabetes Problem Solving subscale with an alpha of 0.65 for early adolescence, 0.69 for middle, 0.71 for late and 0.69 for the total sample. For stages, early adolescence had the poorest alphas (α= 0.62 to 0.75) of all the stage groups. However, about 60% (9 out of 15) of the alpha scores for the age stages were considered to be respectable in the 0.70-0.80 range while 13% were in the good range (α= 0.80-0.84) for middle and late adolescents on the Collaboration with Parents subscale. The number of items for each subscale with stage specific and total sample alpha reliability co-efficient, mean and standard deviation are listed in Table 16.

Table 16. Reliability for Internal Consistency

| subscale | # of items | Early | Middle | Late | Total | Mean Score | SD |
|---|---|---|---|---|---|---|---|
| Collaboration with Parents | 13 | .72 | .80 | .84 | .84 | 13.82 | 6.94 |
| Diabetes Care Activities | 15 | .62 | .78 | .76 | .74 | 30.87 | 6.15 |
| Diabetes Problem Solving | 7 | .65 | .69 | .71 | .69 | 16.10 | 3.58 |
| Diabetes Communication | 10 | .75 | .73 | .68 | .73 | 16.85 | 5.13 |
| Goals | 7 | .71 | .75 | .76 | .74 | 14.16 | 3.33 |

### *Subscale Descriptives*

Descriptive statistics were calculated for each of the dependent variables. The measures of central tendency and Cronbach's alpha reliabilities were calculated for each of the subscales by adolescent stage. The mean, standard deviation (SD), median, possible and actual range for each of the subscales are listed in Table 17.

Table 17. Subscale Descriptive Statistics

| | Early | Middle | Late |
|---|---|---|---|
| | 13-14 | 15-16 | 17-21 |
| | (*n*=163) | (*n*=159) | (*n*=182) |
| Collaboration with Parents | | | |
| Possible Range 0-39 | | | |
| Mean | 18.01 | 13.89 | 10.02 |
| SD | 5.73 | 6.41 | 6.19 |
| Median | 18.00 | 13.00 | 9.00 |
| Actual Range | 4.0-38.00 | 1.0-33.00 | 0.00-29.00 |
| Diabetes Care Activities | | | |
| Possible Range 0-45 | | | |
| Mean | 31.81 | 30.50 | 30.36 |
| SD | 5.28 | 6.53 | 6.48 |
| Median | 32.00 | 30.00 | 31.00 |
| Actual Range | 18.00-42.00 | 16.00-45.00 | 13.00-45.00 |
| Diabetes Problem Solving | | | |
| Possible Range 0-21 | | | |
| Mean | 15.31 | 16.03 | 16.86 |
| SD | 3.62 | 3.62 | 3.35 |
| Median | 16.00 | 17.00 | 17.00 |
| Actual Range | 5.00-21.00 | 3.00-21.00 | 4.00-21.00 |
| Diabetes Communication 0-30 | | | |
| Possible Range | | | |
| Mean | 16.69 | 16.48 | 17.31 |
| SD | 5.15 | 5.29 | 4.96 |
| Median | 17.00 | 16.00 | 17.00 |
| Range | 2.00-28.00 | 3.00-28.00 | 4.00-30.00 |
| Goals | | | |
| Possible Range 0-21 | | | |
| Mean | 13.80 | 14.21 | 14.44 |
| SD | 3.17 | 3.52 | 3.29 |
| Median | 14.00 | 14.00 | 15.00 |
| Range | 3.00-21.00 | 4.00-21.00 | 7.00-21.00 |

## Data Analysis by Aim

### *Specific Aim 1*

Specific aim 1: Examine differences in self-management behaviors (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals) for early, middle and late adolescence.

The difference in self-management behaviors by stage of adolescence were determined by ANOVA. This robust technique was chosen to determine if group means for the three stages of adolescence (early, middle, and late) differ from one another in the areas of Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals. Descriptive statistics were reviewed to check that data met the assumptions for ANOVA. The outcome variable distribution was compared within each stage of adolescence and stage-specific variances of the outcome variables were compared using Levene statistic test to verify the assumption of constant variance.

A one-way ANOVA was used to compare stages of adolescence (early, middle, and late) with self-management scores on Collaboration with Parents, Diabetes Care Activities, Diabetes Problems Solving, Diabetes Communication and Goals, at the 0.05 level. There were no significant differences between early, middle and late adolescence groups on the means from the scores on the Diabetes Care Activities ($F$ (2,501) = 2.857, $p$ =.058), Diabetes Communication ($F$ (2,501) = 1.242, $p$=.290), and Goals ($F$ (2,501) =1.628, $p$=.197) subscales. Significant differences were found among adolescent groups for the self-management behaviors of Collaboration with Parents, ($F$(2,501) = 73.212, $p$=.000) and Diabetes Problem Solving,($F$(2,501) =8.312, $p$=.000). Table 18 summarizes the ANOVA results

Table 18. Analysis of Variance for Differences in Self-Management

| | Sum of Squares | *df* | Mean | F | P-Value |
|---|---|---|---|---|---|
| Collaboration with Parents *(N*=489) | | | | | |
| Between Groups | 5489.551 | 2 | 2744.775 | 73.212 | .000** |
| Within Groups | 18782.828 | 501 | 37.491 | | |
| Total | 24951.434 | 503 | | | |
| Diabetes Care Activities (*N*=473) | | | | | |
| Between Groups | 215.207 | 2 | 107.603 | 2.857 | .058 |
| Within Groups | 18867.213 | 501 | 37.659 | | |
| Total | 19082.420 | 503 | | | |
| Diabetes Problem Solving (*N*=498) | | | | | |
| Between Groups | 207.415 | 2 | 103.708 | 8.312 | .000** |
| Within groups | 6250.857 | 501 | 12.477 | | |
| Total | 6458.272 | 503 | | | |
| Diabetes Communication (*N*=498) | | | | | |
| Between Groups | 65.457 | 2 | 32.728 | 1.242 | .290 |
| Within Groups | 13202.699 | 501 | 26.353 | | |
| Total | 13268.156 | 503 | | | |
| Goals (*N*=495) | | | | | |
| Between Groups | 36.164 | 2 | 18.082 | 1.628 | .197 |
| Within Groups | 5565.251 | 501 | 11.108 | | |
| Total | 5601.415 | 503 | | | |

**p<.05

### *Multiple Comparisons*

Bonferoni adjustment analyses were used for those subscales with significant findings to determine the nature of the pairwise differences between all age groups. Multiple comparisons were computed for the between differences on the three adolescent stage groups for Collaboration with Parents and Diabetes Problem Solving. Table 19 summarizes the Bonferroni post hoc tests for Collaboration with Parents and Table 20 summarizes post hoc for Diabetes Problem Solving.

### *Collaboration with Parents*

A one -way ANOVA comparing scores for Collaboration with Parents during early, middle and late adolescence revealed early adolescents (*m* = 18.01, *sd* = 5.73) scored higher than middle adolescents (*m* = 13.89, *sd* = 6.41) and those in the middle adolescent stage scored significantly higher than those in late adolescence (*m* = 10.02, *sd* = 6.19). Adolescence in the early (*m* = 18.01, *sd* = 5.73) stage also scored significantly higher than those in the late (*m* = 10.02, *sd* = 6.19) stage of adolescence. The mean scores on Collaboration with Parents show an incremental decline in collaboration with parents as adolescents move through stages. Table 19 shows the post hoc analysis for the ANCOVA model for Collaboration with Parents.

Table 19. Post Hoc Analysis for Differences in Collaboration with Parents for Early, Middle and Late Adolescent Group

| Bonferroni Post Hoc Tests | | | | | | |
|---|---|---|---|---|---|---|
| | Age Category | | | Mean Difference | SE | PValue |
| | Early | Middle | Late | | | |
| Early | | X | | 4.116 | .682 | .000** |
| | | | X | 7.989 | .660 | .000** |
| Middle | X | | | -4.116 | .682 | .000** |
| | | | X | 3.872 | .664 | .000** |
| Late | X | | | -7.982 | .660 | .000** |
| | | X | | -3.872 | .664 | .000** |

** $p<.05$

*Diabetes Problem Solving*

Diabetes Problem Solving scores differed significantly between early ($m = 15.31$, $sd. = 3.62$) and late ($m = 16.86$, $sd = 3.35$) adolescent stage groups. There were no significant differences found between early ($m = 16.03$, $sd = 3.62$) and middle ($m = 16.03$, $sd = 3.62$) or middle ($m = 16.03$, $sd = 3.62$) and late ($m = 16.86$, $sd = 3.35$) adolescent stages. The higher mean Diabetes Problem Solving scores found in the late adolescent group correlate with a higher degree of problem solving in this group when compared to those in the early or middle adolescent stage group. Table 20 displays the summary of the ANOVA and Bonferroni Post Hoc Tests for Diabetes Problem Solving during early, middle, and late adolescence.

Table 20. Post Hoc Analysis for Differences in Diabetes Problem Solving for Early, Middle and Late Adolescent Groups

| Bonferroni Post Hoc Tests | Age Category | | | Mean Difference | SE | P Value |
|---|---|---|---|---|---|---|
| | Early | Middle | Late | | | |
| Early | | X | | -.726 | .393 | .196 |
| | | | X | -1.549 | .380 | .000** |
| Middle | X | | | - .726 | .396 | .196 |
| | | | X | - .822 | .383 | .097 |
| Late | X | | | -1.549 | .380 | .000** |

** p<.05

*Specific Aim 2*

Specific aim 2: Examine whether the roles of the covariates (regimen, DOI, gender) in self-management behaviors vary by stage of adolescence.

ANCOVA was used to analyze the data. It is a method used to control for variables that cannot be randomized, yet may have a relation to or affect the variable under study. It combines ANOVA with a regression model that measures the differences among group means. In this case, regimen, DOI and gender were considered covariates and were adjusted to allow for comparison of means among stage and self-management behaviors. Thus Tables 21,24,27, 30 and 32 display adjusted means for each of the five self-management behaviors by stage and for the total sample.

Model assumptions were checked and met making this an appropriate model for analysis. Linear associations between each self-management behavior and DOI and constant variance across different genders and regimens were analyzed. The mean DOI for late adolescence (*m* = 8.01, *sd* = 4.17) was higher than early (*m* = 5.82, *sd* = 3.44) and middle (*m*=6.74, *sd* =3.69). The colinearity between adolescent stage and DOI was checked using linear regression with adolescent stage and DOI as predictors. The diagnostics revealed no problems with colinearity making this an appropriate method for this aim.

After controlling for regimen, DOI and gender, a one-way between subjects ANCOVA was calculated to examine the effect of stage of adolescence on self-management (Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals). Interactions of stage with regimen, DOI, and gender were examined for each self-management behavior. Each interaction was added separately to the model and then removed before adding a different interaction. The interactions were rerun for each of the between subject groups and those that were not statistically significant were omitted. Effects for each of the dependent variables were reviewed and the ANCOVA results show differences between the adolescent stages in two of the five subscales; Collaboration with Parents (*F*(2,498)= 72.80, *p*=.000) and Diabetes Problem Solving (*F*(2,498)= 6.59 , *p*= .002) shown in Table 22 and 28 respectively. The results did not differ from the ANOVA model thus the adjustment for the covariates did not have a major impact on the dependent variable. The ANCOVA results for each dependent variable are described in more detail below.

### *Collaboration with Parents*

Descriptive statistics were computed for the adolescent stages and covariates for the Collaboration with Parents subscale. Throughout all stages those with flexible regimens had lower means on the Collaboration with Parents subscale. After controlling for regimen, there were significant differences between early adolescents (*m* = 18.01, *sd* = 5.73) who scored higher than middle adolescents (*m* = 13.89, *sd* = 6.41). Those in middle adolescence *(m* = 13.89, *sd* = 6.41) scored significantly higher than those in late adolescence (*m* = 10.02, *sd* = 6.19). Adolescents in the early stage (*m* = 18.01, *sd* = 5.73) also scored higher than those in the late stage of adolescence (*m* = 10.02, *sd* = 6.19) on the Collaboration with Parents subscale. Those participants who had flexible regimens (*m*=13.16, *sd*= 6.68) had significantly lower scores on the Collaboration with Parents subscale than those with conventional regimens (*m* = 15.01, *sd* = 7.26) in the total sample, which was similar for all three stages. However the interaction between stage and regimen was not statistically significant (*F*(2,498)= .494, *p* = .611).

The interaction between stage and gender was not significant (*F*(2,498) = 2.091, *p*=.125) although females had higher means and higher standard deviation (*m* = 18.52, *sd* = 6.47) than males (*m* = 17.52, *sd* = 4.93) during early adolescence. This changed during middle adolescence where females had lower means (*m*= 13.68, *sd* = 6.64) than males (*m* = 14.10, *sd*= 6.22) and more equal standard deviations. This trend continued through late adolescence when males had higher mean scores (*m*= 10.77, *sd* = 6.73, ) than females (*m*= 9.06, *sd* = 5.31).

A Pearson correlation coefficient was calculated to assess the relationship between subjects' scores on the Collaboration with Parents subscale and DOI for each adolescent stage and the total sample. A nonsignificant weak positive correlation was found for early (*r*(163) = .131, *p* = .096) and middle (*r*(159) = .096 , *p* = .228) stages. A weak negative correlation that was significant was found for late adolescence (*r*(182) = -.158, *p* = .034) and similarly for the total sample (*r*(504) = -.107, *p*= .016). DOI is not related to Collaboration with Parents during early and middle adolescence, but in late adolescence longer DOI was associated with less collaboration with parents. However, although the correlations with DOI changed direction for early and middle versus late adolescence, those differences aren't large enough to be statistically significant. Table 21 gives details of the descriptive statistics for the Collaboration with Parents subscale considering gender, regimen, and DOI within each adolescent stage separately.

Table 21. Descriptive Statistics and Pearson Correlations: Collaboration with Parents

| | | Early<br>(13-14)<br>*n*=163 | Middle<br>(15-16)<br>*n*=159 | Late<br>(17-21)<br>*n*=182 | Total<br>(13-21)<br>*N*=504 |
|---|---|---|---|---|---|
| Gender | | | | | |
| Male | | | | | |
| | Mean | 17.52 | 14.10 | 10.77 | 13.90 |
| | SD | 4.93 | 6.22 | 6.73 | 6.66 |
| Female | | | | | |
| | Mean | 18.52 | 13.68 | 9.06 | 13.73 |
| | SD | 6.47 | 6.64 | 5.31 | 7.26 |
| Regimen | | | | | |
| Flexible | | | | | |
| | Mean | 17.22 | 13.39 | 9.27 | 13.16 |
| | SD | 5.46 | 6.05 | 6.87 | 6.68 |
| Conventional | | | | | |
| | Mean | 19.69 | 14.57 | 11.51 | 15.01 |
| | SD | 5.46 | 6.87 | 6.37 | 7.26 |
| DOI | | | | | |
| Correlation | | r=.131 | r=.096 | r= -.158 | r= -.107 |
| P value | | .096 | .228 | .034** | .016** |

** p<.05

The ANCOVA model did not detect any significant effect modification by stage. After controlling for each of the covariates, differences between the means of scores for the Collaboration with Parents subscale indicate a decline in Collaboration with Parents while moving through stages. There was a significant effect with the covariate regimen and Collaboration with Parents (*F*(1,498) = 11.96 = *p* = .001), with lower mean scores for those on flexible regimens (*m*= 13.16 , *sd*= 6.68) over conventional (*m* = 15.01, *sd*=7.26). There was no effect modification of regimen to stage (*F*(2,498) = .494, *p* = .611). DOI was also not significantly related to Collaboration with Parents (*F(*16,458) = 1.393= *p* = .140) nor did it provide statistically significant interactions with stage of adolescence (*F*(27, 458) = .77, *p* = .780). Similarly, gender had no significant effect with Collaboration with Parents (*F*(1,

498) = .472, *p* = .492) and no effect modification of regimen by stage (*F*(1, 498) = 2.091, *p* = .125). Table 22 displays the ANCOVA models testing covariates effect modification by stage of adolescence Collaboration with Parents.

Table 22. Analysis of Covariates on Dependent Variable Collaboration with Parents

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 438.823 | 1 | 438.123 | 11.961 | .001** |
| Stage | 4924.311 | 2 | 2462.15 | 66.974 | .000** |
| Stage * Regimen | 36.29 | 2 | 18.14 | .494 | .611 |
| Error | 18307.710 | 498 | 36.76 | | |
| Adjusted R Square = .238 | | | | | |
| DOI | 829.615 | 16 | 51.85 | 1.393 | .140 |
| Stage | 4150.64 | 2 | 2075.32 | 55.760 | .000** |
| Stage* DOI | 783.10 | 27 | 29.04 | .770 | .780 |
| Error | 17044.64 | 458 | 37.21 | | |
| Adjusted R Square = .059 | | | | | |
| Gender | 17.626 | 1 | 17.626 | .472 | .492 |
| Stage | 5531.526 | 2 | 2765.763 | 75.386 | .000** |
| Stage * Gender | 156.264 | 2 | 78.132 | 2.091 | .125 |
| Error | 18604.574 | 498 | 37.359 | | |
| Adjusted R Squared = .234 | | | | | |

** p<.05

To determine main effects one-way between-subjects ANCOVA was calculated to examine the main effects of regimen, duration of illness and gender. Regimen was significantly related to Collaboration with Parents (*F*(1,498) = 11.93, *p* = .001) with those on flexible regimens (*m*=13.169, *sd*= 6.68) having less Collaboration with Parents than those on conventional regimens (*m*=15.01, *sd*=7.26). DOI and gender were not significantly related to Collaboration with Parents (*F*(1, 498) = .079, *p*=.779) and (*F*(1, 498)=.558, *p*= .455) respectively. Table 23 displays the ANCOVA model for the Collaboration with Parents subscale.

Table 23. One Way Analysis of Covariates on Collaboration with Parents

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 439.162 | 1 | 439.162 | 11.937 | .001** |
| DOI | 2.900 | 1 | 2.900 | .079 | .779 |
| Gender | 20.537 | 1 | 20.537 | .558 | .455 |
| Stage | 5303.817 | 2 | 2651.908 | 72.803 | .000** |
| Error | 18321.199 | 498 | 36.790 | | |

Adjusted R Squared = .238

** p< .05

*Diabetes Care Activities*

Descriptive statistics show that males have significantly lower total mean scores (*m*=30.06, *sd* = 5.85) on the Diabetes Care Activities subscale than females (*m* = 31.78, *sd* = 6.36) as well as lower mean scores in all the stage groups. As expected, those with flexible regimens have higher means (*m* = 31.53, *sd* = 6.30) for care activities than those with conventional regimens (*m* = 29.38, *sd* = 6.77).

Pearson correlation coefficient was calculated for the relationship between subjects' scores on the Diabetes Care Activities subscale and the DOI for each adolescent stage as well as the total sample. A nonsignificant weak negative correlation was found for early (*r*(163) =

-.030, *p* = .702), late (*r*(182) = -.027, *p*= .718) stages and similarly for the total sample (*r*(504) = **-.**033, *p*= .456)**.** Middle adolescence was the only stage with a nonsignificant, but positive correlation between DOI and the Diabetes Care Activities subscale (*r*(159) = .021, *p*= .797). Table 24 gives details of the descriptive statistics for the Diabetes Care Activities subscale considering gender, regimen, and DOI within each adolescent stage separately.

Table 24. Descriptive Statistics and Pearson Correlations: Diabetes Care Activities

| | Early<br>(13-14)<br>*n*=163 | Middle<br>(15-16<br>*n*=159 | Late<br>(17-21)<br>*n*=182 | Total<br>(13-21)<br>*N*=504 |
|---|---|---|---|---|
| Gender | | | | |
| Male (*n*=84) | | | | |
| Mean | 31.07 | 29.13 | 29.97 | 30.06 |
| SD | 5.00 | 6.43 | 5.96 | 5.85 |
| Female (*n*=79) | | | | |
| Mean | 32.61 | 31.88 | 30.85 | 31.78 |
| SD | 5.48 | 6.37 | 7.09 | 6.36 |
| Regimen | | | | |
| Flexible | | | | |
| Mean | 32.16 | 31.66 | 30.85 | 31.53 |
| SD | 5.18 | 6.41 | 6.29 | 5.98 |
| Conventional | | | | |
| Mean | 31.07 | 28.91 | 29.38 | 29.69 |
| SD | 5.45 | 6.40 | 6.77 | 6.30 |
| DOI | | | | |
| Correlation | r=.-030 | r=.021 | r= -.027 | r= -.033 |
| P value | .702 | .797 | .718 | .456 |

** p<.05

The ANCOVA model did not detect any significant effect modification by stage. After controlling for each of the covariates, differences between the means of scores for the Diabetes Care Activities subscale indicate a decline in care activities while moving through stages, however, this was not statistically significant. There were significant associations with regimen and Diabetes Care Activities (*F*(1,498) = 9.642, *p* = .002) but no effect modification of regimen to stage (*F*(2,498) = .776, *p* = .261)**.** DOI was also not significantly related to Diabetes Care Activities (*F(*16,458) = .861, *p* = .586) nor did it provide statistically significant interactions with stage of adolescence (*F*(27, 458) = .734. *p* = .837). Gender was statistically significant between subject effects with Diabetes Care Activities (*F*(1, 498) = 10.060, *p* = .002) but did not have a significant effect modification by stage

($F(1, 498) = 1.021$, $p = .361$). Table 25 displays the ANCOVA models testing effect modification by stage of adolescence.

Table 25. Analysis of Covariates on Dependent Variable Diabetes Care Activities

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 357.135 | 1 | 367.135 | 9.642 | .002** |
| Stage | 199.873 | 2 | 99.937 | 2.698 | .068 |
| Stage * Regimen | 57.473 | 2 | 28.736 | .776 | .261 |
| Error | 18445.274 | 498 | 37.039 | | |
| Adjusted R Square = .024 | | | | | |
| DOI | 541.84 | 16 | 33.86 | .861 | .586 |
| Stage | 143.32 | 2 | 71.664 | 1.870 | .155 |
| Stage* DOI | 754.92 | 27 | 27.96 | .734 | .837 |
| Error | 170509.28 | 458 | 38.23 | | |
| Adjusted R Square = .008 | | | | | |
| Gender | 372.376 | 1 | 372.376 | 10.060 | .002** |
| Stage | 210.884 | 2 | 105.442 | 2.849 | .059 |
| Stage * Gender | 75.556 | 2 | 37.778 | 1.021 | .361 |
| Error | 18433.605 | 498 | 37.015 | | |
| Adjusted R Squared = .024 | | | | | |

**p<.05

The one-way ANCOVA model was run to determine the main effects of regimen, duration of illness and gender on Diabetes Care Activities. Regimen was significantly related to Diabetes Care Activities (*F*(1,498) = 9.75, *p* = .002) with those on flexible regimens (*m* 31.53, *sd*= 6.30) having higher scores on the diabetes care actives subscale than those on conventional regimens (*m*=29.38, *sd*=6.77). DOI was not significantly related to Diabetes Care Activities (*F*(1, 498) = .323, *p*=.570). Interestingly, the main effects of gender were found to be significant (*F*(1, 498)= 9.752, *p*= .002) with males having lower total mean scores (*m*=30.06, *sd* = 5.85) on the Diabetes Care Activities subscale than females (*m* = 31.78, *sd* = 6.36). The ANCOVA model is displayed in Table 26

Table 26 One Way Analysis of Covariates on Diabetes Care Activities

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 355.235 | 1 | 355.235 | 9.752 | .002** |
| DOI | 11.784 | 1 | 11.784 | .323 | .570 |
| Gender | 355.235 | 1 | 355.235 | 9.752 | .002** |
| Stage | 152.264 | 2 | 76.132 | 2.090 | .125 |
| Error | 18140.68 | 498 | 36.427 | | |

Adjusted R Squared = .040

**p<.05

*Diabetes Problem Solving*

Diabetes Problem Solving scores tended to increase as adolescents aged. Interestingly, the scores for males stayed almost exactly the same from early (*m*= 15.72, *sd* 3.51) to middle (*m*= 15.71, *sd*= 3.87), where female scores increased from early (*m*=14.87, *sd*= 3.71) to middle (*m*=16.36, *sd*= 3.34) stages. Although not enough to be statistically significant, the trend was reversed when males increased their scores from middle (*m*=15.71, *sd*=3.87) to late (*m*=17.0, *sd*= 2.94), where females did not show a big difference from middle (*m*=16.36, *sd*=3.34) to late (*m*=16.67, *sd* =3.85) adolescence. Overall, Diabetes Problem Solving showed significant (*F*(2,498)=6.596, *p*=.002) increases as adolescents moved through stages. Means increased from early (*m*=15.31, *sd*=3.62) to middle (*m*=16.03, *sd*=3.62) and late (*m*=16.86, *sd*=3.35) adolescence.

Pearson correlations for DOI show no significant relationships between Diabetes Problem Solving and DOI for the early *(r(*163) = .076, *p* =.337) and late adolescent (*r*(182)= .091, *p* = .091) stage groups**.** However, a weak but significant relationship was found between middle adolescents *(r(*159) = .166, *p* =.036) as well as for the total sample (*r*(159) **=** .159, *p* = .000). Table 27 summarizes the descriptive statistics for the Diabetes Problem Solving subscale considering gender, regimen, and DOI within each adolescent stage separately.

Table 27. Descriptive Statistics and Pearson Correlations: Diabetes Problem Solving

| | Early<br>(13-14)<br>*n*=163 | Middle<br>(15-16)<br>*n*=159 | Late<br>(17-21)<br>*n*=182 | Total<br>(13-21)<br>*N*=504 |
|---|---|---|---|---|
| Gender | | | | |
| Male | | | | |
| Mean | 15.72 | 15.71 | 17.00 | 16.21 |
| SD | 3.51 | 3.87 | 2.94 | 3.47 |
| Female | | | | |
| Mean | 14.87 | 16.36 | 16.67 | 15.97 |
| SD | 3.71 | 3.34 | 3.85 | 3.70 |
| Regimen | | | | |
| Flexible | | | | |
| Mean | 15.94 | 16.54 | 17.68 | 16.76 |
| SD | 3.11 | 3.35 | 2.56 | 3.07 |
| Conventional | | | | |
| Mean | 15.22 | 15.34 | 15.22 | 14.90 |
| SD | 4.09 | 3.89 | 4.09 | 3.35 |
| DOI | | | | |
| Correlation | r= .076 | r=.166 | r= .126 | r= .159 |
| P value | .337 | .036** | .091 | .000 ** |

** p<.05

There were no significant effect modifications by stage in the ANCOVA model. After controlling for each of the covariates, differences between the means of scores for Diabetes Problem Solving gradually increased for each stage group but, as noted, at different time points for males and females. There were significant associations with regimen and Diabetes Problem Solving (*F*(1,498) = 34.82 = *p* = .000) with higher mean scores for those on flexible regimens (*m*= 16.76 , *sd*= 3.07) over conventional ones (*m* = 14.90, *sd*=3.35)**.** There was no effect modification of regimen to stage (*F*(2,498) = .1.357, *p* = .259). DOI was significantly related to Diabetes Problem Solving (*F*(16,458) = 1.789, *p* = .030), but it did not provide statistically significant interactions with stage of adolescence (*F*(27, 458) = 1.173. *p* = .253). Gender had no significant associations with Diabetes Problem Solving (*F*(1, 498) = .317, *p* = .574) and no effect modification of regimen by stage (*F*(1, 498) =

1.875, *p* = .154). The ANCOVA models testing effect modification by stage of adolescence are summarized in Table 28.

Table 28 One Way Analysis of Covariates on Dependent Variable Diabetes Problem Solving

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 406.247 | 1 | 406.27 | 34.826 | .000** |
| Stage | 175.114 | 2 | 87.557 | 7.506 | .001** |
| Stage * Regimen | 31.647 | 2 | 15.824 | 1.357 | .259 |
| Error | 5809.193 | 498 | 11.665 | | |
| Adjusted R Square = .091 | | | | | |
| DOI | 345.674 | 16 | 21.605 | 1.789 | .030** |
| Stage | 90.94 | 2 | 45.470 | 3.765 | .024** |
| Stage* DOI | 382.468 | 27 | 14.165 | 1.173 | .253 |
| Error | 5531.997 | 458 | 12.079 | | |
| Adjusted R Square = .059 | | | | | |
| Gender | 3.945 | 1 | 3.94 | .317 | .574 |
| Stage | 203.555 | 2 | 101.779 | 8.176 | .000** |
| Stage * Gender | 56.678 | 2 | 23.339 | 1.875 | .154 |
| Error | 6199.693 | 498 | 12.449 | | |
| Adjusted R Squared = .030 | | | | | |

**p<.05

As illustrated in Table 29, all of the associations with the independent variables in the ANCOVA model for Diabetes Problem Solving were significant with the exception of gender which was not significant (*F*(1,498) = .641, *p* =.424). Performance in Diabetes Problem Solving showed significant (*F*(2,498)=6.596, *p*=.002) incremental increases in mean scores as adolescents moved through stages with means increasing from early adolescence (*m*=15.31, *sd*= 3.62) to middle (*m*=16.03, *sd*= 3.62) and late (*m*=16.86, *sd*= 3.35). The covariates of regimen and duration provided significant regression effects for the dependent variable Diabetes Problem Solving (*F*(1,498) = 33.988, *p* =.000) and (*F* (1,498) = 6.730, *p*= .010) respectively. Those with flexible regimens (*m*= 16.76, *sd*= 3.07) scored significantly (*F*(1,498) = 33.98, *p*= .000) higher on Diabetes Problem Solving than those with conventional regimens (*m*= 14.90, *sd*= 3.35)**.** The main effect for DOI was significantly (*F*(1, 498) = 6.730, *p*= .010)and positively related to Diabetes Problem Solving (*r*(504) = .159, *p* = .000) suggesting increased problem solving for those with longer DOI even after adjusting for stage. Table 29 shows the ANCOVA model for Diabetes Problem Solving.

Table 29. One Way Analysis of Covariates on Diabetes Problem Solving

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 392.952 | 1 | 392.952 | 33.988 | .000** |
| DOI | 77.809 | 1 | 77.809 | 6.730 | .010** |
| Gender | 7.407 | 1 | 7.407 | .641 | .424 |
| Stage | 147.815 | 2 | 73.907 | 6.596 | .002 ** |
| Error | 5956..018 | 498 | 11.561 | | |

Adjusted R Squared = .100

**p<.05

*Diabetes Communication.*

The descriptive statistics for the Diabetes Communication subscale were computed for the three adolescent stage groups and the total sample. Throughout all stages those with flexible regimens scored higher means on the Diabetes Communication subscale. There were significant (*F*(1,498) = 7.94, *p* = .005) differences between males and females with males having more varied level of Diabetes Communication between stages. Mean scores for males in early (*m* = 16.10, *sd* = 4.40), middle (*m*=15.59, *sd*=5.34) and late (*m*= 16.97, *sd*=5.20) adolescence were more fluctuant than females who remained more constant throughout early (*m* = 17.31, *sd* = 5.81), middle (*m* = 17.42, *sd* = 5.10) and late(*m* = 17.76, *sd* = 4.64) adolescence.

A Pearson correlation coefficient was calculated to assess the relationship between subjects' scores on the Diabetes Communication subscale and DOI for each adolescent stage and the total sample. There were no significant correlations found between DOI and Diabetes Communication. Although not significant, adolescent stage and DOI correlations were found to be positive in early (*r*(163) = .059, *p* = .453) and middle (*r*(159) = .063 , *p* = .433) stages and similarly for the total sample (*r*(504) = .034, *p*=.443). There was a weak negative correlation that was not significant between DOI and Diabetes Communication in late adolescence (*r*(182) = -.040, *p* = .593). Therefore, DOI was not related to Diabetes Communication**.** Table 30 gives details of the descriptive statistics for the Diabetes Communication subscale considering gender, regimen, and DOI within each adolescent stage separately.

Table 30. Descriptive Statistics and Pearson Correlations: Diabetes Communication

| | Early<br>(13-14)<br>*n*=163 | Middle<br>(15-16)<br>*n*=159 | Late<br>(17-21)<br>*n*=182 | Total<br>(13-21)<br>*N*=504 |
|---|---|---|---|---|
| Gender | | | | |
| Male | | | | |
| Mean | 16.10 | 15.59 | 16.97 | 16.27 |
| SD | 4.40 | 5.34 | 5.20 | 5.02 |
| Female | | | | |
| Mean | 17.31 | 17.42 | 17.76 | 17.50 |
| SD | 5.81 | 5.10 | 4.64 | 5.18 |
| Regimen | | | | |
| Flexible | | | | |
| Mean | 16.96 | 16.97 | 17.57 | 17.19 |
| SD | 5.16 | 5.39 | 5.08 | 5.19 |
| Conventional | | | | |
| Mean | 15.80 | 15.80 | 16.81 | 16.23 |
| SD | 5.13 | 5.11 | 4.96 | 4.98 |
| DOI | | | | |
| Correlation | r= .059 | r=.063 | r= -.04 | r= .034 |
| P value | .453 | .433 | .593 | .443 |

** p<.05

There was no significant effect modification by stage in the ANCOVA model. After controlling for each of the covariates, there were no significant differences between the means of scores for the Diabetes Communication as adolescents move through stages. There were no significant associations with regimen and (*F*(1,498) = 3.733, *p* = .054) this subscale or DOI (*F*(1,498) = 7.21, *p* =.773). Similarly, there was no effect modification of covariate regimen to stage (*F*(2,498) = .073, *p* = .930) or DOI to stage (F(16,458) = 1.089, *p*=.348). Gender had a significant association with Diabetes Communication (*F*(1, 498) = 7.940 *p* = .005), but no effect modification to stage (*F*(1, 498) = .472, *p* = .624)**.** Table 31 displays the ANCOVA models testing effect modification by stage of adolescence for Diabetes Communication.

Table 31. One Way Analysis of Covariates on Dependent Variable Diabetes Communication

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 98.190 | 1 | 98.190 | 3.733 | .054 |
| Stage | 58.001 | 2 | 29.000 | 1.102 | .333 |
| Stage * Regimen | 3.825 | 2 | 1.912 | .073 | .930 |
| Error | 13100.464 | 498 | 26.306 | | |

Adjusted R Square = .003

| | | | | | |
|---|---|---|---|---|---|
| DOI | 304.502 | 16 | 19.031 | .721 | .773 |
| Stage | 56.296 | 2 | 28.148 | 1.067 | .345 |
| Stage* DOI | 775.558 | 27 | 28.724 | 1.089 | .348 |
| Error | 12083.256 | 458 | 26.383 | | |

Adjusted R Square = .000

| | | | | | |
|---|---|---|---|---|---|
| Gender | 206.896 | 1 | 206.896 | 7.940 | .005** |
| Stage | 71.403 | 2 | 35.701 | 1.370 | .255 |
| Stage * Gender | 24.578 | 2 | 12.289 | .472 | .624 |
| Error | 12977.330 | 498 | 26.059 | | |

Adjusted R Squared = .012

**p<.05

The ANCOVA model did not detect any significant effect modification by stage. After controlling for each of the covariates, there were no differences between the means of scores for the Diabetes Communication subscale (*F*(2, 498) = 1.426, *p* = .306) as adolescents move through stages. However, there were significant associations with gender and Diabetes Communication (*F*(1,498) = 7.50, *p* = .006), with overall lower mean Diabetes

Communication scores for males for the total sample (*m*= 16.27 , *sd*= 5.02) than females (*m* = 17.50, *sd*=5.18) indicating poorer communication for males. Table 32 displays the ANCOVA model for Diabetes Communication.

Table 32. Analysis of Covariates on Dependent Variable Diabetes Communication

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 93.827 | 1 | 93.827 | 4.023 | .058 |
| DOI | 2.023 | 1 | 2.023 | .079 | .780 |
| Gender | 195.648 | 1 | 195.648 | 7.550 | .006** |
| Stage | 61.559 | 2 | 36.884 | 1.426 | .306 |
| Error | 12904.498 | 498 | 25.913 | | |

Adjusted R Squared = .018

** p <.05

*Goals*

Descriptive statistics were computed for the adolescent stages and covariates for the diabetes goal subscale. Throughout all stages as well as with the total sample, those with flexible regimens had higher means on the Goal subscale but not enough to be statistically significant. Similarly, the differences in mean scores on the Goals subscale between males and females in different stage groups and for the total sample were small and not significant.

During early adolescence, the correlation between Goals and duration of illness was weak and negative, but it was not significant (*r* (163) = - .0156, *p*=.477). Although the Pearson correlation coefficients for the relationship between subjects' scores on the Goals subscale and DOI were positive in the three stages, they were not significant. Table 33 shows the descriptive statistics and Pearson correlations for the Goals subscale.

Table 33. Descriptive Statistics and Pearson Correlations: Goals

| | Early<br>(13-14)<br>*n*=163 | Middle<br>(15-16)<br>*n*=159 | Late<br>(17-21)<br>*n*=182 | Total<br>(13-21)<br>*N*=504 |
|---|---|---|---|---|
| Gender | | | | |
| Male | | | | |
| Mean | 13.92 | 13.75 | 14.13 | 13.95 |
| SD | 3.18 | 3.93 | 3.38 | 3.49 |
| Female | | | | |
| Mean | 13.67 | 14.68 | 14.83 | 14.39 |
| SD | 3.17 | 3.01 | 3.16 | 3.14 |
| Regimen | | | | |
| Flexible | | | | |
| Mean | 13.85 | 14.25 | 14.27 | 14.27 |
| SD | 3.24 | 3.11 | 3.26 | 3.26 |
| Conventional | | | | |
| Mean | 13.68 | 14.16 | 13.98 | 13.96 |
| SD | 3.04 | 4.05 | 3.13 | 3.46 |
| DOI | | | | |
| Correlation | r= -.056 | r=.062 | r= -.095 | r= .059 |
| P value | .477 | .435 | .201 | .187 |

** p<.05

The ANCOVA model did not show any significant effect modification by stage, suggesting that Goals did not differ by stage. The lack of effect modification across stages suggested that the association with goals was relatively constant across adolescent stages. Table 34 summarizes the covariate analysis for the Goals subscale.

Table 34. One Way Analysis of Covariates on Dependent Variable Goals

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 11.465 | 1 | 11.465 | 1.030 | .311 |
| Stage | 25.549 | 2 | 12.774 | 1.147 | .318 |
| Stage * Regimen | 8.636 | 2 | 4.318 | .388 | .679 |
| Error | 5544.354 | 498 | 11.133 | | |
| Adjusted R Square = .000 | | | | | |
| DOI | 252.159 | 16 | 15.760 | 1.473 | .105 |
| Stage | 25.364 | 2 | 12.682 | 1.185 | .307 |
| Stage* DOI | 360.712 | 27 | 13.360 | 1.249 | .184 |
| Error | 12083.256 | 458 | 10.700 | | |
| Adjusted R Square = .039 | | | | | |
| Gender | 17.626 | 1 | 17.626 | .472 | .492 |
| Stage | 5611.735 | 2 | 2805.868 | 75.106 | .000** |
| Stage * Gender | 156.264 | 2 | 78.132 | 2.091 | .125 |
| Error | 18604.574 | 498 | 37.359 | | |
| Adjusted R Squared = .226 | | | | | |

** p<.05

The one way ANCOVA model showed no significant main effects of regimen, DOI and gender for the Goals subscale. The relationship of regimen to goals was not significant (*F*(1,498) = .988, *p* = .321) and DOI showed no main effects (*F*(1, 498)= .681, *p*=.409). Similarly, gender was not found to be a significant variables (*F*(1,498)= 2.281, *p* = .132).

Table 35. Analysis of Covariates on Goals

| Source | Sum of Squares | df | Mean Square | F | P Value |
|---|---|---|---|---|---|
| Regimen | 10.945 | 1 | 10.945 | .988 | .321 |
| DOI | 7.552 | 1 | 7.552 | .681 | .409 |
| Gender | 25.281 | 1 | 25.281 | 2.281 | .132 |
| Stage | 30.023 | 2 | 15.012 | 1.355 | .259 |
| Error | 5518.885 | 498 | 11.082 | | |

Adjusted R Squared = .005

### *Summary*

This chapter provided descriptive statistics from the sample and reliability coefficients for internal consistency for each of the self-management behavior subscales. Additionally, this chapter reported results from the analysis examining the differences in the self-management behaviors of Collaboration with Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication, and Goals for early, middle, and late adolescence. Significant associations between the adolescent stages and specific self-management behaviors were described. Further, age-related differences and associations with self-management behavior differences were examined with potential risk and protective factors (regimen, DOI, and gender) as covariates. Associations between the age groups and the interaction of the covariates on the dependent variable were also included in this chapter.

The ANOVA model (Aim 1) illustrated significant between group differences for the Collaboration with Parents and Diabetes Problem Solving subscales. Post-hoc analysis conducted determined a steady decline in collaboration with parents as adolescents moved through stages. Conversely, post-hoc analysis showed an increase in diabetes problem solving as adolescents aged, but only significant differences between early and late adolescence.

The ANCOVA model (Aim 2) showed no significant effect modification for the covariates and stage on any of the subscales. However, there were significant associations between regimen and Collaboration with Parents, Diabetes Care Activities and Diabetes Problem Solving, but not for Diabetes Communication or Goals, and, as such, suggests the use of flexible versus conventional regimens is important to consider when looking at self-management behaviors. DOI showed no significant associations with any of the self-management behaviors with the exception of problem solving, where those with longer DOI had better Diabetes Problem Solving scores. Analysis of the covariate of gender revealed significant associations with Diabetes Care Activities and Diabetes Communication with females having significantly higher scores than males across stages and for the total sample on both subscales. The main effects of the covariates were significant for regimen on the Collaboration with Parents, Diabetes Care Activities and Diabetes Problem Solving subscales. For DOI there were significant relationships on the Diabetes Problem Solving subscale only. Lastly, gender provided main effects for Diabetes Care Activities and Diabetes Communication only.

# Chapter V

# Discussion

## Introduction

This chapter presents a discussion of the findings from Chapter IV. It includes a discussion of the findings in the context of the Self and Family Management Framework, the empirical literature and new findings. Study limitations and future research implications are also presented.

## Discussion of Findings

Although there are limited comprehensive estimates of T1D among US youth (Lipton, 2007), the SEARCH for Diabetes in Youth Study Group (2007) has reported T1D to be the most common form of diabetes in children age 0-19 years. They reported the incidence is highest among non-Hispanic white children and the incidence rates for adolescents 10-14 per 100,000 are 32.9 (*CI* 95%, 30.2-35.8) and for adolescents 15-19 (*CI* 95%, 13.2-17.1). The total number of white youth (per 100,000 person-years) with T1D was reported to be 518 for youth aged 10-14 years and 231 for those aged 15-19. The next most frequent affected by TID is African Americans, with 75 youth aged 10-14 and 39 aged 15-19. Therefore, the population from this study closely mirrored that of the general adolescent population with T1D in being predominantly white (83% White) with only 8 % Black, 2% Asian, 5% Hispanic, 9% Indian or Alaskan Native, Other or Multiple). The SEARCH study group (2007) also reported a fairly equal division between genders as was the case with this study (52% male).

## Self-Management Behaviors

### *Collaboration with Parents*

The Self and Family Management Framework recognizes the inclusion of family as an integral component of self-management behaviors.  Although family is important at any age, it is even more important to youth since diabetes self-management decisions are best made in partnership with parents (ADA, 2005).  Empirical work also highlights the importance of shared responsibility (teamwork) for diabetes self-care through early to middle adolescence (Anderson, Brackett & Laffel, 1999; Helgeson, et al.,  2007) with a gradual transition to independent decision making when the adolescent achieves developmental milestones that begin during middle to late adolescence and end in adulthood (Hanna & Guthrie, 2003, Helgeson et al., 2007).  However, the most common motivation for parents to transition their adolescents from dependence to independence in diabetes self-management is the adolescent's chronological age (Palmer et al., 2004).  However, findings from several studies highlighted the importance of shared responsibility (teamwork) for diabetes self-care through early to middle adolescence (Anderson, Brackett & Laffel, 1999; Helgeson et al., 2007) with a gradual transition to adolescent independent decision-making in late adolescence and adulthood (Hanna & Guthrie, 2003).

There is a significant amount of data to support a steady decline in parent involvement in diabetes self-management as adolescents age (Guthrie, Bartsocas, Chabot & Konstantinova, 2003, LaGreca, 1998, Wiebe et al., 2005) even though the ADA (2005) recommends parental (family) involvement until late adolescence.  The findings from this study supported the extant literature that suggests adolescents' transition from a dependent to a more independent role based on age.  The analyses from the multiple comparisons between adolescent stages showed a steady inverse relationship between stage of adolescence and the Collaboration with Parents subscale. As adolescents aged, they collaborated significantly less with parents. However, it is still important for youth to continue to collaborate with parents in an advisory role even for older adolescents, a role described by Anderson, Brackett & Laffel, (1999) as featuring interdependent interactions.

### *Diabetes Care Activities*

Although there was a total alpha coefficient of 0.74 for the total sample, when analyzed by stage, early adolescence had lower alphas (0.62) and, as such, results must be considered with caution. However, middle and late adolescence had acceptable Cronbach's alphas of 0.78 and 0.76 respectively. There were no significant differences in Diabetes Care Activities scores between stage groups. Since the youngest adolescents in this study were 13 years of age, it is likely that many of them were already performing most of their Diabetes Care Activities. Schilling and colleagues (2006) found that by early adolescence (11-15), many youth were doing much of their own care activities. Another reason for the lack of significant findings may be that the majority ($n$=331, 64%) of the subjects in this study used a flexible versus conventional regimen *requiring* more frequent diabetes activities. The ADA (2005) recognizes that even with the use of flexible regimens most adolescents perform many of their activities, (e.g. blood glucose monitoring, insulin injections and boluses) by early school age (8-11 years), likely explaining why there were no significant differences between stage groups. Differences in diabetes care activities may be more influenced by personal and family characteristics than age.

### *Problem Solving*

The findings associated with this subscale must be considered with caution. There was a total alpha coefficient of 0.69 for all ages and when analyzed by stage, early and middle adolescence were also only minimally acceptable (0.65 and 0.69 respectively).

However, for late adolescence the Cronbach's alpha was respectable at 0.71. Diabetes Problem Solving scores differed significantly between early and late but not between early and middle or late and middle. Problem solving involves combining the synthesis of knowledge and past experiences with an application of skills into a behavior (Hill-Briggs, 2003). Because of the increased cognitive function needed to successfully problem solve, it. was anticipated that those in the late adolescent group would have achieved a higher degree of problem solving given the development of abstract thinking and problem solving skills. Similarly, although abstract thinking begins during middle adolescence, it does not fully develop until late adolescence, possibly explaining the significant findings between early and late and lack thereof between early and middle and middle and late

Recent research reports have focused on the relationship between problem solving and metabolic control or adherence measures (Cook et al., 2001) and therefore are difficult to place into context with this study. Prior diabetes self-management measurement among adolescents with T1D did not include problem solving per say but rather elements of problem solving measured through diabetes care activities (Schilling et al., 2002). It may be that problem solving is conceptually difficult to measure hence contributing to the minimally acceptable alphas. Also, it may be that age groupings for stage are not conceptually valid. Lastly, although adolescents are capable of problem solving, it does not necessarily mean the decisions they make are directed at optimal outcome self-management behaviors.

### *Diabetes Communication*

Communication is an integral part of diabetes self-management. Communication is especially important in adolescence because negative communication can cause conflict which has a detrimental influence on self-management (Dashiff, Hardeman & Mc Lain, 2008). Further, communication may facilitate parental diabetes-related support to adolescents (Hanna, Juarez, Lenss, & Guthrie, 2003), a factor that research has demonstrated to have positive impact on adolescents' self-management behaviors (Dashiff, et al., 2008, Miller & Drotar, 2007). Communication is essential to negotiate the responsibilities and outcomes of diabetes self-management with parents, teachers, peers and health care providers (HCP). While no studies were found to measure communication per say, there was a fair amount of studies focusing on conflict. There is a connection between communication and conflict, as prior work suggested that negative communication resulted in increased conflict (Dashiff et al., 2008). Further, some work suggests that conflict *frequency* does not necessarily change during adolescence, conflict *affect* (intensity) does and peaks during middle adolescence (Hanna, Juarez, Lenns & Guthrie, 2003; Laursen, Coy & Collins, 1998). This was indirectly corroborated in this study, as there was no significant difference in communication *frequency* as adolescents moved through stages as was similar to what was found by Dashiff et al. (2008). Nonsignificant findings could indicate that other factors besides age may influence diabetes communication and, as such, should be explored further, perhaps in qualitative inquiry.

### *Goals*

The concept of self-management has not included goals until recently (Schilling, Grey & Knafl, 2002). To date, this is the first study to consider goals as an essential attribute of self-management. Reliability analyses for this subscale were acceptable for early ($\alpha$ =0.71) middle ($\alpha$= 0.74) and late ($\alpha$ =0.76) as well as for the total sample ($\alpha$ = .74). There was an nonsignificant increase in goals as adolescents aged and a lack of significant associations between goals and any of the covariates. This was not surprising given goals require future-oriented thinking. Even the most developmentally advanced adolescents remain present minded and may not *begin* to consider future consequences until 18-20 years of age (Mercer, 1979, Neinstien, 1996). This phenomenon has been reported in the literature by Winger, O’Donnell & Ritholz (2001) who found that adolescent’s perceptions were that parents focused on the future, where adolescents focused on the present when considering parental support for their daily diabetes management.

An additional consideration would include the notion that goals may not be a behavior, but rather a driving force behind behavior and as such may be a mediator of self-management during adolescence. The influence of goals on diabetes self-management has not been well studied and therefore is not well understood. There may be other variables other than those in this study that may be important and behaviors aimed at goal attainment represent important developmental milestones during adolescence and should be studied so HCPs and parents can support adolescents in setting and attaining their goals.

## Covariate Analysis

### *Regimen*

Although regimen was not found to have any effect modification on stage for any of the subscales, regimen was the only covariate found to have a significant relationship with three of the subscales (Collaboration with Parents, Diabetes Problem Solving and Diabetes Care Activities). Perhaps the most interesting findings were the significant associations between regimen and Collaboration with Parents subscale throughout all stages of adolescence. Those with flexible regimens had lower scores indicating less collaboration with parents than those with conventional regimens. This was surprising given that flexible regimens are more complex. In addition, according to the Self and Family Management Framework (Grey, et al., 2006), more complex care would result in greater self-management needs, requiring more frequent diabetes care activities and hence more opportunity or need for collaboration with parents. In this study, the association was inverse; those with flexible regimens (who required more self-management) collaborated with parents less than those with conventional regimens.

The constant nature of a flexible regimen may not lend itself well to a collaborating with parents, given adolescents spend increasingly more time away from parents, especially as they age. Parents may also perceive their adolescent as requiring less collaboration since they are likely performing much of their self-management independently so that when there are opportunities for collaboration it may be considered unnecessary by both parent and/or adolescent. Flexible regimens require more “constant” care and adolescents may need to become more independent earlier by necessity. Further exploration is warranted to determine why flexible regimens resulted in less parental collaboration, especially when a flexible regimen can put adolescents at a higher risk for complications (DCCT, 1994) and is the current recommendation for those over age 7 (ADA, 2005). Also important to consider is that adolescents who have self-management responsibility that exceed their problem solving skills, cognitive development and maturity may have difficulty negotiating the demands of a complex flexible regimen (Wysokci et al., 2006). In this study, those adolescents on flexible regiments had overall higher Diabetes Problem Solving scores for than did those on conventional regimens. Also, the means on the Diabetes Problem Solving subscale scores for those on conventional regimns were relatively constant across the three stage groups, where there was a steady increase across the stages for those on flexible regimens.

There were significant differences between the flexible and conventional regimen groups on the Diabetes Care Activities subscale that were expected given that flexible regimens require more frequent blood sugar testing and insulin adjustment (DCCT, 1993). This supports the Self and Family-Management Framework that suggests that more complicated (flexible) regimens require a greater degree of self management, at least for the activities associated with the self-management.

There were significantly higher Diabetes Problem Solving scores for those adolescents on flexible verses conventional regimens. It is not clear if using a flexible regimen contributes to an improvement in problem solving or if adolescents with a natural ability or developmental readiness to problem solve are chosen by their HCP and parents to utilize this regimen. Also, during the DCCT (1993), youths on flexible regimens received much more involvement from HCPs from multiple disciplines compared to those using conventional regimens. This support is likely to contribute to problem-solving self-management behaviors, although the DCCT level of support does not necessarily reflect the degree of support adolescents received in this study.

### *Duration of Illness*

An interesting although negative finding was the lack of significant relationship between DOI and Collaboration with Parents, so that the degree of parental collaboration did not correlate with the length of time the adolescent has had diabetes in this study. The lack of correlation between DOI and Collaboration with Parents supports findings from Faulkner & Chang (2007) who reported DOI was not a significant predictor of self-management. This suggests that parents and adolescents do not consider the length of time in which the adolescent has been diagnosed and hence living with diabetes when decreasing the amount of collaboration, but rather were influenced by other factors such as age (Palmer et al., 2004) or type of family management style (Knafl, Dietrick & Gallo, 2008). This is important given that intuition would dictate that more newly diagnosed youth would likely require more adult guidance. Only one study (Streisand et al., 2002) found that longer DOI was associated with better self-care activities and another (Springer, et al., 2006) found longer DOI to be associated with worse metabolic control. It is unlikely that the experience that comes with self-managing a chronic condition for long durations of time has no impact on how an individual goes about living with the daily demands self-management. It may be that while DOI may not be related to some elements of self-management (collaboration with parents, diabetes care activities, diabetes communication or goals), it may be an important factor in others such as decision making or diabetes problem solving.

In fact, the main effect for DOI was significantly and positively related to Diabetes Problem Solving suggesting those with a longer DOI have increased problem solving. This was expected because, as noted, increased experience in living with a chronic illness would improve an individual's ability to solve diabetes problems. Cognitive processes during late adolescence move significantly toward thinking more abstractly, and individuals in this age group are able to solve problems more quickly. Also, with longer duration of illness, adolescents may have had more diabetes management experiences and overall diabetes knowledge that they can apply to helping them better problem solve diabetes issues.

The framework used to guide this study reported the relationship of trajectory (proxy measure in this study: DOI) to self-management to be variable and multifactoral. This was supported by the mix of significant and non-significant findings for DOI with some of the self-management subscales in this study. This is likely due to the lack of conceptual quality and measurement issues posed by using length of time since diagnosis for a proxy measure of chronic illness trajectory as depicted in the framework.

### *Gender*

The issue of gender in the self management diabetes literature is conflicting, partially because all the studies reviewed used a different definition or measure of self-management**.** Several studies found females had worse metabolic control than males **(**LaGreca, et al., 1995, Skinner & Hampson, 2001, Springer, et al., 2006, Storch, et al., 2006) but the use of metabolic control as an outcome measure made it difficult to synthesize the literature. Other studies reported females having better self -management than males (Dashiff, McCaleb, Cull, 2006; Naar-King, Idolski, Ellis, Frey & Templin, 2006; .Streisand et al., 2002). Still others reported no difference in self-management behaviors between males and females (Lagreca, Swales, Klemp, Madigan & Skyler, 1995) with some reporting no differences after controlling for confounding variables such as warmth and caring (Faulkner& Chang, 2007), socioeconomic status (Springer, 2006) and self-reliance (Mansfield et al., 2004). However, in this study, there were some associations between specific elements of self-management (Diabetes Care Activities and Diabetes Communication) that were significantly associated with gender, but others that were not (Collaboration with Parents and Goals)**.** This likely contributes to why the literature is conflicting.

The literature suggests that females perform more frequent (Dashiff, McCaleb & Cull, 2006, Naar-King, Idolski, Ellis, Frey & Templin, 2006, Streisand et al., 2002) and independent (Schmidt, 2007, Williams, 1999) diabetes care activities than males. This study's findings partially support the literature with females practicing more frequent diabetes care activities, but not more independently since there were no gender differences on the Collaboration with Parents subscale. Females in this study also had higher Diabetes Communication scores than did males. It may be secondary to personality characteristics inherent in females that allow for increased communication related to their diabetes as some studies have reported. Males may avoid diabetes care activities, especially in social situations where they may be more prone to diabetes-related bullying (Storch, 2006) and may even have chosen their regimen based on the need to perform diabetes care activities in school (Williams, 1999). However, this study did not support greater independence with females as there were no significant gender differences on the Collaboration with Parents subscale. A major difference between this study and those in the extant literature are a nearly equal gender mix and large sample size, hence increasing generalizability where previous studies tended to be smaller with less gender equality.

This study's framework suggested that female gender may be a risk factor for less than optimal self-management. Females may neglect their own needs so that they may care for others and as such practice less overall self-management than males. Since this is a family framework this assumption may be more applicable for adult females versus adolescents.

Some studies have reported diabetes mismanagement among females. For example, some studies have reported increased episodes of DKA, hospitalizations and eating disorders among females (Brink, 1997; Cohn, Cirillo, Wingard, Austin & Roffers, 1997; Neurmark-Sztainer, et al., 2002; Springer et al., 2006). There are also some studies that have measured and reported *mis*management behaviors in the female population (eating disorders and insulin omission) (Ackard, et al., 2008; Cohn, et al., 1997; Hanna & Guthrie, 1999; Hanna & Guthrie, 2001; LaGreca, Swales, Klemp, Madigan & Skyler, 1995). Although this study was not meant to measure mismanagement, it is curious that gender differences that were detected showed females practicing better (in some aspects) self-management than males.

## Limitations

As a research method secondary analysis has some disadvantages. One limitation was that all of the variables of interest may not be available due to a lack of data hence the decision to exclude variables of interest or use of a proxy measure. For example, the secondary dataset in this study did not allow for analysis of socioeconomic factors that may affect adolescent diabetes self-management. Other limitations include some of the demographic variables from the parent study sample. Although the sample from this study resembled the general population of adolescents with TID (ADA, 2005), it has limited diversity for race and ethnicity. This limited the exploration of potential cultural differences among age stages for adolescents. Subjects admitted to the parent study were between the ages of 13 and 21 years, this limited the availability of the very early adolescents int his secondary analysis. This is problematic, given adolescence may begin much earlier than age 13, depending upon cognitive, psychosocial, emotional, physiological, physical and psychomotor development, by most accounts. Despite limitations, the age grouping was selected because the available proximity of chronological age ranges within each adolescent stage. This would account for developmental differences inherent within each participant and as such this study provides a good starting point to study adolescents by stage.

As noted, the alpha reliability for some of the subscales was found to be low and, as such, results must be interpreted with caution for these subscales. The alpha scores from the parent study were slightly higher secondary to the exclusion criteria of those not living at home in this study. The SMOD-A has only recently been developed and has not been subject to redevelopment and testing. Therefore, using the instrument in subsequent studies will assist researchers and clinicians to assess individual subscale items and further develop this instrument. Additionally, the lower alphas for adolescent stage groupings may reflect a conceptual problem with age groupings. In fact, with the exception of Diabetes Communication, alpha scores for the stage with the largest span of chronological age, late adolescence (17-21), were actually higher than alphas for total sample.

Lastly, the Self-and Family Management framework depicts self-management as a moderator or mediator variable that has a direct influence on outcome variables (metabolic control, quality of life). Perhaps, self-management as a construct would be better suited as an outcome variable since there are other variables that influence self-management. Although some of the covariates in this study were shown to have an influence on elements of self-management, there are a wide variety of mediators and moderator variables (socio-economic status, insurance status, mental health status) that may influence self-management, but were not controlled for in the secondary analysis. The framework had pragmatic utility for guiding inquiry surrounding chronic health conditions, but was only recently developed, limiting its use in empirical work. Further, prior to use in the parent study it was developed from the adult literature and used in only one study with an adult population, therefore, it may need modifications to guide inquiry with the adolescent population.

### *Implications for Future Research*

The study findings and comparison to the empirical literature suggest that a common definition of self-management should be adopted to guide future empirical research (Harris et al., 2000; Lorig & Holman, 2003; Sawyer & Aroni, 2005; Schilling et al., 2002). Having a more uniform definition assists researchers to aggregate data to find meaningful implications for clinical practice.

Findings from several studies highlighted the importance of shared responsibility for diabetes self-care through early to middle adolescence (Anderson, Brackett & Laffel, 1999; Helgeson, et al., 2007). Berg, Schindler and Maharajh (2008) showed that collaboration was linked to interpersonal enjoyment, with less enjoyment of collaboration for both adolescent and mother with advancing age which may be a factor in declining parental collaboration. The decline in Collaboration with Parents as adolescents aged in this study may not have been gradual given the significant differences between adolescent stages with a relatively short time span between age groupings and warrants further exploration. Although this would be expected, less collaboration with developmental advancement, increases in some of the other self-management behaviors indicated advancing independence (Diabetes Care Activities, Diabetes Communication and Goals) were not found as adolescents aged. This warrants further exploration, perhaps a qualitative grounded theory study that may enhance understandin of how decisions are made to decrease parental collaboration and how the decline influences other aspects of self-management. Similarly, the covariate of regimen should be explored further to determine why those with flexible regimens collaborated less with parents. This is important since the ADA (2005) recommends those over age seven utilize a flexible regimen and because of the increased risk of acute diabetes complications (e.g. DKA) associated with flexible regimen use in the adolescent population. Focus group methdology might be used to learn more about why those with more complicated regimens collaborate less with parents to better understand the clinical implications of choosing a flexible over conventional regimen.

Further, there were some elements of self-management, specifically Diabetes Communication and Goals, that are still not well understood and should be explored further. Communication is an important aspect of self-management and it is not clear what factors (e.g. personality characteristics) influence effective communication. Findings from this study shed some new light on the role of gender in self-managment in adolescents. One area to consider would be intentions of self-management, especially in females. It is still not well understood why females have more episodes of DKA and hospitalizations than males. This would assist to understand motivations behind self-management behaviors, especially for females. DOI was found to be a significant covariate in this study for Problem Solving only. It might be useful to understand the daily self-management activities for each of the adolescent stages for those who are more recently diagnosed as well as those adolescents who have been living with the condition for a long time. A focus group method with adolescents who have shorter, longer and middle range of years since diagnosis of DOI would assist in understanding nuances in the trajectory of a life-altering chronic condition.

### *Clinical Implications*

The study findings provide some useful data for clinicians, specifically the Collaboration with Parents subscale and the co-variate of regimen. The extant literature along with the findings of this study support chronological age as a common factor in decreasing parental collaboration. This is important for clinicians to consider the development of the adolescent and encourage an optimal amount of collaboration regardless of the age of the patient. Regimen also seems to influence several aspects of self-management (Collaboration with Parents, Diabetes Care Activities and Problem Solving) and these elements should be considered when making the decision to put youth on a specific type of regimen. Also, the lack of significant associations with DOI and self-management (exception: Diabetes Problem Solving) was noteworthy and clinicians should not make an overall assumption that those living with a diabetes for longer periods of time are necessarily better or worse self-managers than those more newly diagnosed.

### *Summary*

This study provides valuable information about adolescents and their self-management practices. Although some of the associations between some of the self-management behaviors as outcome variables by stage were significant, the adjusted R square values are relatively small for all models. Unfortunately, only a small explanation in variance was found. These findings suggests that while self-management behaviors may be associated with adolescent stage, factoring in covariates regimen, DOI or gender, other factors likely play a role in adolescent self-management behaviors as well. Further, the conceptual framework used to guide this study did not include self-management as an outcome variable but rather a mediator for condition outcomes, which differed appreciably from the statistical models used in this analysis, as well as comparative literature for this study. A common definition of self-management should be adopted to avoid conceptual and measurement confusion in order to synthesize literature to provide implications for practice.

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